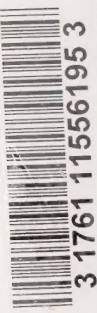


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Waiting lists and Waiting Times for Health Care in Canada:

More Management!! More Money??

**Paul McDonald
Sam Shortt
Claudia Sanmartin
Morris Barer
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June 1998



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Acknowledgements

During the course of this project we had the benefit of very fruitful discussions with Charles Wright, Greg Stoddart and Ken Bassett. We are also grateful to the members of the Federal/Provincial/Territorial Advisory Committee on Health Services, for comments and suggestions based on a presentation of preliminary results, and to the many individuals across the country who kindly agreed to be interviewed, or who took the time to complete our questionnaires and respond to our requests for information. The project was funded by Health Canada, through a competition administered by its Synthesis and Dissemination Branch.

WAITING LISTS AND WAITING TIMES FOR HEALTH CARE IN CANADA

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SYNOPSIS

With rare exceptions, wait lists in Canada, as in most countries, are non-standardized, capriciously organized, poorly monitored, and (according to most informed observers) in grave need of retooling. As such most of those currently in use are at best misleading indicators of access to care, and at worst instruments of misinformation and propaganda. Where wait list data are carefully and accurately compiled and routinely monitored, as is the case for cardiac procedures in Ontario, and radiation oncology in British Columbia, for example, the public clearly benefits. In most other situations, what lists there are do not provide a fair and transparent basis for either managing patients or allocating resources. There is consequently an urgent need for a concerted investment in this country in the design and development of information and management systems that can provide the public with a greater sense of confidence about access to, and quality of care. Such an initiative affords Canada an opportunity to join countries such as New Zealand, which have made clear commitments in this area. Without such commitments, the chaotically acquired and misleading data on wait lists and times that currently form much of the basis for policy (re)action, will continue to haunt efforts to improve the precision with which resource allocation decisions are made, both within health care, and between health care and other important determinants of the health of Canadians.

PREAMBLE

The last decade has seen substantial restructuring of health care in Canada. In every province and territory, changing fiscal circumstances (in particular slower overall economic growth) have created pressures on the health care system to do more despite slower rates of growth in resources. This has led to often widespread operational reorganization (or at least the appearance thereof), leading examples of which would be the rush to "regionalization" and pressures to move patients "closer to home". The extent of some of these changes has raised concerns, among health care professionals and the public, about deterioration in the quality of traditional institution-based services. A primary example of this has been the growing concern about deterioration in access to care, most often portrayed in the form of increased numbers of patients, or unacceptable lengths of time, on waiting lists. These concerns are often portrayed by the media as new "crises", despite the fact that there is relatively little objective information available on waiting times or waiting lists, in Canada or anywhere else, and despite the fact that wait lists long predate any of the recent restructuring activity. Since Canadians and all levels of government in the country remain committed to the basic principles of equitable access to necessary and effective health care, such concerns have been reflected in growing government attention to the issues of wait lists and wait times. It was this climate that led to Health Canada commissioning this work.

The Projects

In November 1997 Health Canada commissioned a number of projects intended to provide¹:

- ▶ a comprehensive critical review and synthesis of published and unpublished literature on the nature, extent, and factors influencing wait lists and wait times;
- ▶ an assessment of current provincial/territorial activities related to the management of wait lists and wait times;

¹ The commissioned work is the result of an RFP issued in October 1997.

- ▶ an assessment of the current state of wait lists and wait times, and of the wait lists currently in use in Canada, for a subset of clinical conditions, and from a variety of perspectives.

The project was undertaken over approximately six months, mid-November 1997 through mid-June 1998, and was comprised of a number of related initiatives:

- ▶ a preliminary appraisal of the literature on wait lists and wait times, to inform development of interview and survey instruments (Chapter 1);
- ▶ interviews with key informants from each provincial/territorial Ministry/Department of Health which identified individual(s) with whom we should speak (Chapter 2);
- ▶ a survey of all large hospitals and all regional health authorities likely to have management responsibility for, or to be accountable for the effects of, wait lists among the populations they serve (Chapter 3);
- ▶ interviews with representatives of a wide range of consumer and other non-government organizations likely to be involved with, or have clear interests in, the topic (Chapter 4);
- ▶ a comprehensive and critical appraisal of the published and unpublished national and international literature on waiting for care. (Chapter 5);
- ▶ the synthesis of the information collected from these modules, for the purposes of developing some policy directions (Chapter 6);
- ▶ the provision of a comprehensive bibliography on wait lists and wait times (References).

This report does not represent the final word on wait lists. Indeed, one of the disturbing findings from our work is how little is known about the extent, nature, or determinants of wait lists and wait times in this country. In this context, the information presented here can serve as a catalyst, a call to arms intended to encourage a full frontal assault on the dismal state of wait lists/times information and accountability in this country.

Chapter 1:

Waiting Times & Waiting Lists for Medical Services in Canada: Key Issues from the Literature

**S.E.D. Shortt, M.D., Ph.D
Queen's Health Policy
Queen's University
Kingston, Ontario**

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EXECUTIVE SUMMARY

This chapter is a preliminary synthesis of the existing Canadian and international literature on waiting times and waiting lists. The major conclusions are as follows:

- ▶ To permit meaningful comparisons between service units, waiting lists must be described in standardized terminology.
- ▶ A variety of methods, each with equity and access implications, exist by which lists are currently created and managed. In Canada most lists are kept by individual physicians or diagnostic / treatment facilities with few attempts at coordination.
- ▶ Waiting is associated with publicly-funded health systems; it signifies the absence of costly excess capacity.
- ▶ There are many contributing causes to growing waiting lists including: poor system coordination, physician and patient behaviour, aging population, technological change, resource reductions and changes in disease patterns.
- ▶ While waiting lists have some benefits, long lists exert an adverse effect on patients and their families, providers, and the health system as a whole.
- ▶ Waiting lists are a poor indicator of the need for a particular service; at best they are a possible reflection of the demand for a service.
- ▶ Waiting lists, depending on their organization, may enhance or detract from equity of access to health services.
- ▶ There is no predictable relationship between resource augmentation and reduction in the size of a waiting list.
- ▶ The availability of private care does not appear to reduce waiting times for publicly-funded care.
- ▶ Methods of varying reliability exist by which appropriate waiting times may be defined for most medical services.
- ▶ The major policy implications of this literature review relate to the need for standardized measures of waiting times, the importance of a greatly enhanced capacity to coordinate knowledge of waiting times on a regional or provincial basis, and the need to begin the process of defining acceptable waits for key service

1.0 Introduction

Since its inception, the state-funded system of health care in Canada has enjoyed chronic popularity. Yet there are signs that Canadians are becoming anxious about the performance of their cherished system, particularly with reference to waiting times for medical services. An Angus Reid poll in 1997, for example, found 63% of respondents believed waiting times for surgery had increased in the preceding year, up from 53% in 1996 (Canadian Medical Association, 1998). Similarly, providers are concerned with the issue of waiting. In Calgary 92% of surveyed family physicians felt their patients faced an unreasonable delay in accessing specialist appointments (Walker, 1998). Finally, provincial governments clearly evince a concern for waiting times. To address the issue two provinces have recently published documents on surgical waiting times in their jurisdictions (Nova Scotia, 1996; British Columbia, 1997).

These examples suggest that waiting times for some medical services are perceived as an issue for a broad range of Canadians and, as such, deserve closer scrutiny. The present document is designed to provide background information on key issues relating to waiting lists and waiting times. It is based on a review of published Canadian and international literature identified by a search of the Medline and HealthStar databases, supplemented by a manual search. It also includes references to significant unpublished Canadian documents.

2.0 Waiting Lists and Times: Definitions, Measurement, Types, and Management

2.1 Introduction

This section defines waiting lists and waiting times, discusses their types and measurement, and describes approaches to their management.

2.2 Definitions

A *Waiting list* is generally held to be a roster of patients awaiting a particular health service. Such lists refer to elective rather than emergency services, though some lists are used for urgent services as well. They occur, in theory, when demand for a service exceeds immediately available supply and are particularly a characteristic of state-funded health care systems in

which there is zero money cost for a service.

Waiting time refers to the length of time required for a patient on the list to receive the desired service. In most jurisdictions the length of time is a function of the manner in which patients enter the list and receive the service. Since methods show considerable variation, the meaning of the term of “waiting time” will vary according to its jurisdictional context.

2.3 Measurement

Gauging the size of a *waiting list* would seem to be a relatively straight-forward task of counting the number of names on the list. Unfortunately, reality is more complex and involves consideration of the following points:

- ▶ Audits of waiting lists in various specialties and jurisdictions (eg. Tomlinson and Cullen, 1992; Lee et al, 1987; Hochuli, 1987; Royal Australian College of Surgeons, 1991; Parmar, 1993) consistently find a significant number of names for whom the service is no longer required through death, deterioration in health status, movement to another community, receipt of the service elsewhere, resolution of symptoms, or inappropriate initial placement on the list.
- ▶ Even after auditing a waiting list, a simple tally of names remains relatively meaningless without additional information from which to create a context for the numbers. First, it is important to know what resources are servicing patients on a list. A lengthy list serviced by one surgeon is of greater concern than a list of the same magnitude shared by several surgeons. The implications of the list can be clarified by creating a ratio between the number of patients on a list and the number of procedures or investigations done in a specified time period (Hanning, 1994). Secondly, it is important to have some sense of the pool of potential patients from which a list is created. This can be done in rough terms by relating the list to the size of the catchment population standardized for age, gender, and ideally, morbidity (Cottrell, 1980). The problem here is accurately defining the catchment area. Finally, this catchment area data should be compared to regional (or provincial) data in what has

been called “standardized waiting list ratios” (SWLR) (Donaldson et al., 1989).

Waiting lists by age are compared to the regional age-stratified population, and the resulting age-specific waiting prevalence ratios are then applied to the same age groups resident in each of the districts comprising the region. This creates an “expected” number of patients who would be on the waiting lists if all catchment districts shared the same waiting experience as the region. The actual number of people on the waiting list of each district can then be expressed as a percentage of the expected number of waiting patients to produce the SWLR.

Measuring *waiting time* is also a complex task. Among the issues are the following:

- ▶ There is no firm consensus as to what chronological interval should be considered the true waiting time (Smith, 1994). Most studies focus on only one segment of a continuum (usually the third or fourth) which includes: the time from onset of symptoms to the decision to seek medical attention; waiting for a primary care assessment; waiting after referral for a specialist appointment; and waiting for receipt of an investigation, treatment, or admission ordered by the specialist.
- ▶ The waiting time experienced by an individual patient is impossible to predict from the number of persons on the list and the rate at which the medical service is dispensed. Many of those patients listed, as noted above, will not require the service, while conversely, new patients with more urgent conditions may be moved to the head of the queue.
- ▶ Equally, however, attempts to express waits as an average of all patient experience at a particular point in time are often uninformative. Since some patients will wait, for various reasons, an unusually long time and most patients are likely to wait varying but lesser lengths of time, the data produces a positively skewed frequency curve demonstrating the characteristics of an F-distribution rather than the bell-shaped normal distribution curve. In this situation, median values will not coincide with mean values, that is, a majority of patients will have been seen prior to the average waiting

time (Shaw et al., 1997). Despite this methodological pitfall, many studies continue to use average waiting times without appropriate data transformation (e.g. Nova Scotia Department of Health 1996).

- Rather than attempting to predict waiting time accurately or calculate it for an average patient on the list at a specific point in time, it may be most accurate to derive waits retrospectively at the point of service provision. Generally, the resulting times will be somewhat lower than those based on a census of patients on a list at a particular time. This difference is analogous to that between prevalence and incidence in epidemiology (Don et al., 1987).

2.4 Types of Waiting Lists

Waiting lists may be classified by the mechanics of their compilation, the category of service they provide, or the principles upon which the list compilation is based. The mechanics of compiling is relatively straightforward to describe: in Canada the majority of waiting lists are compiled by individual physicians; less commonly, hospitals will co-ordinate the lists of all physicians in a particular specialty and institutions generally compile the waiting lists for diagnostic services; rarely, for scarce services deemed to be often urgently needed, as in the case of coronary artery by-pass surgery in Ontario, waiting lists may be created at a provincial level.

The types of services which waiting lists generally apportion are either a discrete service (e.g. diagnostic procedure, physician encounter) or admission to a health care facility. These categories may be further divided according to the broad level of urgency into critical/elective and acute/chronic respectively.

Waiting lists can also be typed according to the implicit or explicit principles on which they are compiled. While there has been little attempt to document this aspect of waiting lists (Doyal, 1995), they appear to fall into four broad categories:

- ▶ *libertarian* - patients are simply added to the list chronologically and receive their service in the order in which they joined the queue
- ▶ *utilitarian* - patients are admitted to a queue if it is thought that their clinical characteristics indicated a sufficient likelihood of benefiting from the receipt of a scarce clinical resource, that is, that their treatment will be cost-effective (Hadorn and Holmes, 1997a; Hadorn and Holmes, 1997b)
- ▶ *egalitarian* - prioritizes on the basis of perceived clinical need to eliminate variation, that is, patients undergo evidence-based triage to ensure equal needs receive equal treatment while dissimilar needs receive dissimilar services (e.g., Basinski et al., 1993)
- ▶ *ad hoc* - may use elements from the above methods and introduces a significant subjective component from the service provider which may accord importance to factors such as race (Eggers, 1995) or employment status (Gaffney and Key, 1995) in an often implicit fashion (Iversen and Nord, 1992)

In theory, then, any list should be able to be classified according to where it is compiled, whether it relates to a service or an admission, the broad level of urgency, and the underlying principle upon which the list is based. Thus a list compiled by a region or province for an elective service that is based on a declared egalitarian principle (e.g., knee replacement) should occasion less concern than lists generated in individual physician's offices for a critical service (e.g., angiography) that appear to be based on ad hoc principles.

2.5 Managing Waiting Lists

Waiting for medical services is often conceived of as analogous to the performance of a relatively orderly queue, that is, movement forward will largely reflect the rate of service provision. In practice, however, this often does not appear to be the case. For example, in the United Kingdom there is evidence that increasing resources for some services for which there is a significant wait has increased rather than decreased waiting list size (Goldacre et al.,

1987). Similarly, in the United States it has been shown that waiting list size will increase for hospitals as a greater percentage (above 70 to 80%) of theoretical capacity is actually opened for service (McQuarrie, 1983). Explanations for why waiting lists do not behave as classic queues and suggestions to deal with these circumstances fall under three general areas to be considered below:

- ▶ *Rationing*: This perspective argues that growing waiting lists are less a sign of poor management than an easily anticipated consequence of deliberate policy decisions concerning allocation of scarce health resources. While long waits may be unfortunate, they are the “price” state-funded systems charge when faced with cost constraints in the provision of service (Lindsay and Feigenbaum, 1984). Viewed in this way any “management” of waiting lists is in reality a broader issue of systemic financial management; lesser interventions will never accomplish any significant change in patterns of waiting as long as central resource decisions remain constant.
- ▶ *Mortlakes*: This theory suggests that what at first appears to be waiting list dysfunction is, in fact, an implicit but deliberate method of assigning low or nil priority to certain types of medical problems. Conditions such as haemorrhoids, hernias or varicose veins comprise a large proportion of U.K. surgical waiting lists. These conditions are distasteful to the public and arouse little concern for their neglect. Equally, they are clinical conditions which hold little therapeutic or research attraction for the medical profession. These unfortunate patients are, in effect, consigned to a stagnant pool - a mortlake - of indefinitely waiting patients for whom no amount of new resources in the system are likely to provide more rapid access to treatment (Frankel, 1989).
- ▶ *Mismanagement*: Many specialties and jurisdictions view growing waiting lists as a problem of resource organization and utilization which is amenable to improved management techniques. Often they are perceived as a largely local problem amenable to local management solutions. The following is a compilation of various management strategies described in the literature:

- **List audits:** A number of studies in the United Kingdom and elsewhere have shown that when long waiting lists are audited by service providers, many individuals on the list are found to have died, moved away, received the service elsewhere, no longer require the service, or refuse the service when offered (Hochuli, 1987; Tomlinson and Cullen, 1992; Mobb et al., 1994). As well, if referring physicians review their list of referred patients, a significant number may be removed from the list for similar reasons (Elwyn et al., 1996). No Canadian list audits have been published.
- **Reassessment:** While experiencing a lengthy wait, patients may undergo a change in their clinical condition which alters their need for a particular surgical service. This change may not be known to their physician such that the patient arrives for a procedure which is cancelled at a time too late to use scarce operating room or diagnostic facilities for another patient on the list. By ensuring periodic reassessment of patients, last minute cancellations can be avoided and lists shortened by removing such patients well in advance (Ross and Watson, 1988). There are no reports of such interventions in Canada.
- **List Clearing:** In the United Kingdom a number of initiatives have been directed at the backlog of patients on a specific waiting list. These projects usually involve minimal extra resources, re-configure existing resources only temporarily, are focussed exclusively on patients who have been on surgical lists over a specified length of time, succeed in reducing the number of patients waiting longer than the specified length, and are of variable long-term efficacy (Mills et al., 1991; Parmar, 1993).
- **Guaranteed maximum waits:** In both the United Kingdom and Sweden the resources necessary to honour maximum wait guidelines have been made available for selected conditions such as coronary bypass grafting (CABG) or cataract surgery. In Sweden this program appears to have partially met its goal by increasing productivity and improving waiting list management (Hanning, 1996).

- **Redirected referrals:** In the United Kingdom it has been shown that general practitioners, if sent monthly bulletins as to waiting times for outpatient consultation and inpatient treatment, are willing to redirect their referrals to the sources with the shorter waits (French et al., 1990).
- **Reduced outpatient contact:** Waiting lists refer to new patients. In order to make room for seeing more new outpatients, various strategies have been adopted by consultants to reduce the number of follow-up visits for previously assessed patients. For example, a U.K. study suggested greater use of telephone contact, devolving management back to general practitioners, and the use of nurse clinicians for selected follow-up (Davies et al., 1994). An Australian group recommend the use of “modular caseload management”, a system which combined regular clinic visits with home health instruction and outreach strategies, so as to accommodate a much larger patient population with considerably reduced waiting time (Hill, 1988).
- **Throughput adjustment:** This management approach considers lengthening waiting lists to be the result of a poor balance between the demand for treatment and the rate at which patients can be treated. The latter rate - throughput - is a function of a complex interaction of the resource implications of different diagnoses, various levels of urgency and different types of treatment. Proper management accords priority to clinically urgent cases, and allocates the remaining resources to the mix of cases likely to be processed most efficiently, thereby reaching optimal throughput (George et al., 1983). It is worth noting that the throughput “blockages” will occur for different specialties at different locations in the patient care process and will demand quite different system adjustment for their elimination (Brunt and Peel, 1989).
- **Waiting list manipulation:** Rather than purging lists of patients no longer requiring service, some health care providers have attempted to change the way lists themselves are constructed. In the U.K. some surgeons have done away with the uncertainty of waiting lists and replaced them with pre-arranged admission dates. This may have reduced the number of patients who do not attend for their admission and the number who are admitted through

emergency departments (Frankel et al., 1991). The problem of “no shows”, that is, patients who do not keep appointments is very high for waiting list patients in the United Kingdom (White, 1980). In one study, for example, prior notification by patients of their intent to miss an outpatient appointment would have reduced waiting time from six months to one week (Turner and Cooke, 1991). However, the problem is by no means confined to Britain; both American and Canadian studies (Parrish et al., 1986; Parker and Froese, 1992) have explored ways of communicating with newly referred patients in order to minimize the no-show rate. This, in turn, allows more patients from the list to be seen, thereby reducing waiting times.

- **Centralized lists:** In many jurisdictions waiting lists, excluding those for hospital-based diagnostic services, are maintained only by individual physicians. This approach inhibits an overall awareness of waiting times for a particular service, allows “gaming” of lists by doctors (e.g., large lists may be taken as an endorsement of particular expertise), permits “gaming” by patients who secure a place on more than one list, and distorts the ability to allocate resources according to accurate projections of utilization. Most importantly, the lack of co-ordinated decision making means significant variation in the severity of need of the patients who receive the service. In contrast, centralized waiting lists servicing the patients of all physicians in a particular specialty, usually surgical, have been shown to be more efficient and accurate (Madhock, 1994; Beverland et al., 1989; Bell, 1988). In Canada such centralization is likely rare. A 1992 study of British Columbia secondary and tertiary care institutions revealed that in 10 of 17 institutions lists were held by individual surgeons, while 7 were maintained by departments of surgery, admissions departments or operating rooms. In 13 of the facilities the decision as to the next patient to be admitted was made by individual surgeons. In selecting the most commonly deployed criteria used to prioritize admissions, responding institutions ranked physician preference first (29%) followed by previous cancellations (24%) and urgency rating (24%). None of the respondents possessed guidelines for compiling or using waiting list data, only two had

computerized lists, and none co-ordinated their lists with nearby institutions (Amoko, 1992). This situation is likely characteristic of most regions of Canada since patients are deemed, by both themselves and their physicians, to “belong” to individual doctors, while pooling of patients on a common list is foreign to the tradition of Canadian practice.

- **Patient prioritization:** Rather than allocating services to patients simply on the basis of the order in which the queue was entered, patients can be prioritized by various methods. By far the most favoured method is based on clinical criteria. The health consequences of long waiting lists can be mitigated substantially by ensuring that patients receive service on the basis of clinical need and within times defined, on the basis of clinical evidence, as appropriate. The Ontario experience since 1991 in operating a province-wide priority-based registry of patients awaiting CABG illustrates the success of such efforts. An evaluation of the early performance of this system concluded that, despite some inequitable variation between hospitals, queuing patients rarely experienced critical cardiac events or extreme delays and variation in individual waiting times reflected primarily clinical acuity (Naylor et al, 1995). Though clinical prioritizing appears to be the methodology most compatible with shared assumptions about equity in health care, other criteria has been proposed. Patients, for example, have been surveyed as to how factors such as age, smoking status or the availability of home support should be used in prioritization (Kee et al., 1997). A less compelling suggestion focuses on the work status of patients, arguing that individuals on sick leave should receive priority.. Data from several countries indicate five to ten percent of patients on waiting lists are on sick leave from employment. The production gains of returning these patients to full-time jobs, coupled with savings from payments for sick benefits, would constitute a national economic dividend. This could be deployed to fund expanded clinical services, thereby reducing the aggregate waiting time for all remaining patients on waiting lists and countering any claims of inequitable queue jumping by the employed (Nord, 1990). However, no evidence is presented that augmenting current funding would reduce waiting

lists (see below, Section 5.4). There is some Canadian evidence that surgeons implicitly take employment status into consideration when determining priority for surgery (Naylor et al.,1992a).

2.6 Summary

This section has established the following conclusions:

- ▶ Waiting lists and times have not been defined or measured in terms which permit ready comparison between jurisdictions.
- ▶ A variety of list management techniques have been deployed by various jurisdictions, the success of which appear to be primarily a function of the degree to which the intervention correctly identifies the primary cause of waiting problems in that specific locality.

3.0 Causes of Waiting for Medical Services

3.1 Introduction

This section will discuss the major causes of waiting for medical services. While the literature contains passing reference to many possible causal factors, compelling empirical validation is often lacking.

3.2 State-funded Health Care Systems

In health care systems which are predominantly state-funded such as those found in the United Kingdom, Canada, New Zealand or Australia, waiting lists are thought to be endemic. This is a product of non-market financing, that is, a divorce between payment and receipt of service (Cullis and Jones, 1985; Bloom and Fendrick, 1987). In contrast, under the entrepreneurial American system, waiting is virtually unknown. This system is distinguished by competition amongst providers who, in order to respond expeditiously to consumer demand, must maintain costly excess capacity. Moreover, since service is rationed on the basis of price, millions of citizens are without access to service, that is, are denied even the opportunity to queue for a service (Naylor, 1991).

State-funded systems do not carry excess capacity which implies some queuing - non-price rationing - will always be present and further, that this queuing will become more pronounced in the face of unusually constrained resources. There is debate whether patients should be seen as “paying” largely with their time or whether cost is better considered the anxiety and potential deterioration occasioned by the waiting process (Cullis and Jones, 1986). Waiting is perceived by some economists as an economically inefficient method of resource allocation since the value of the service to the individual waiting may decay with time. That is, the service may be less valued when received than it would have been by another individual who was discouraged from joining the queue because of its length (Lindsay and Feigenbaum, 1984; Cullis and Jones, 1986). In those state-funded systems which permit a significant private option the situation is somewhat more complicated. Some economists argue, despite empirical evidence to the contrary, that, though price setting below market-clearing level will still produce a queue, the size of the public queue will vary according to the number of citizens who choose to pay for private care. This choice, in turn, has been shown to be related not merely to supply and demand factors, but also to macro-economic indicators such as consumer prices and interest rates (Goddard et al., 1995).

3.3 Health Care System Organization

Several organizational features of health care systems appear to foster the growth of waiting lists. Most significant among them are the following (see also section 2.4 above):

- ▶ decentralized responsibility for list generation, as in the case of Canada where lists are almost exclusively created in the offices of individual physicians or hospital diagnostic departments rather than by a regional authority (Amoko et al., 1992)
- ▶ lack of inter-regional co-ordination for waiting lists
- ▶ the capacity to control utilization in part of the supply sector of the health care system (e.g., the availability of hospital services through global budget restrictions), without a commensurate and coordinated ability to manage important elements of the demand sector (e.g., patterns of physician requests for scarce resources)

- ▶ a reliance for resource allocation planning on traditional patterns of utilization rather than on needs- and evidence-based methodologies

3.4 Resource Reductions

It is often assumed that resource reductions lead to longer waiting lists. This certainly appears to be the belief of the Canadian public. When polled by the Angus Reid Group in 1997, a majority of respondents felt waiting times for a variety of services - emergency room care (68%), nursing care in hospitals (65%), surgery (59%) - had increased as a result of under-funding (Angus Reid Group, 1997). Possibly because the relationship is seen as self-evident, the academic literature relating increased waiting to specific resource reductions is scant.

In the United Kingdom different opinions are offered on the precise effect of resource constraints. Using data from a general hospital surgical service it has been shown that a modest reduction in beds will lead to clear costs savings but at the expense of a dramatic increase in waiting times (Ellis, 1991). In contrast, Frankel argues that “long waiting times have at most a tenuous relationship with any lack of ... resources” (Frankel, 1989, p.56). The waiting phenomenon is confined to relatively few specialties and within these specialties, relatively few diagnoses. These conditions are perceived by the health system as relatively minor annoyances associated with aging but of little medical interest. This perception, rather than inadequate resources, explains the waiting lists for these procedures.

Beyond this debate, at least one study has modelled the effect of *adding* instead of removing surgical consultant resources and suggested the effect will be to increase waiting times (Frost, 1980). As will be discussed in greater detail in section 5.4 below, however, the connection between varying resource levels and waiting is actually complex and often unpredictable.

3.5 Technology

The impact of developments in medical technology, though often cited as contributing to increased waiting, is not certain. Some forms of technology clearly inspire the formation of lists. For example, with the introduction of the anti-rejection drug, cyclosporine in the early 1980s, the number of heart transplantations rapidly increased (Leonhardt et al., 1994). The

success of this technology appeared to stimulate heightened demand which, since the number of donor organs remained stable, lead to longer waiting lists (Chen et al., 1996). At the same time, however, other technical developments in cardiac pharmacology created drugs which allowed some patients to be safely removed from transplant waiting lists (Levine et al., 1996).

In contrast, technical advances in the use of size-reduced adult donor organs for paediatric liver transplant recipients was predicted to significantly reduce waiting lists and waiting list mortality (de Goyet et al., 1993). Since the procedure lacks the modest discretionary element associated with adult cardiac transplant, it is unlikely that procedural success will stimulate increased demand.

In Canada waiting lists for kidney transplant, despite increasing numbers of transplant operations, began to rapidly accelerate in the early 1980s (Jeffery et al., 1986). This would appear to illustrate a technology, the success of which, enhances its own demand. The rapid rise in angioplasty (Higginson et al., 1994) and of laparoscopic gallbladder surgery (Cohen et al., 1996) may be further examples. In the latter case, though the hospital stay by case was dramatically reduced, the number of procedures increased. Patients with other disorders seeking hospitalization may have had more ready access to beds previously occupied by gallbladder patients, but gallbladder patients themselves now faced the likelihood of growing queues for laparoscopic surgery.

It is worth noting one final point about technology: while on occasion it may create new demand leading to new or longer waiting lists, its absence in the face of growing need can be an equally potent stimulus to queue formation. The growing hiatus in Ontario during the late 1980s between diagnosis of a cancer and the initiation of radiation therapy has been attributed to a lack of treatment technology (Mackillop et al., 1994). It seems reasonable to conclude that the availability or introduction of medical technology can both augment or diminish waiting lists.

3.6 Population Aging

Many of the services for which there is contemporary concern about growing waiting lists are services such as cataract surgery or hip and knee replacement that are predominantly associated with older age groups. These older age groups are growing and there is concern that their heightened demand for constrained resources creates waiting lists. Even when it is acknowledged that at present only persons 75 years of age and over consume a disproportionate amount of health services, aging remains of concern in reference to the provision of specific services (Rosenberg and Moore, 1997). For example, concern has been expressed in Ontario that access to dialysis is increasingly delayed despite a doubling of the population-based rate of dialysis from 1982 to 1991. During this period the average age of patients receiving hemodialysis increased from 50 to 57. Patients 75 and over demonstrated the most rapid compound growth rate at 17.3% annually. These patients represented 5% of new patients in 1982 and 13.5% in 1992, a change consistent with national and United States data (Choudhry and Naylor, 1994).

These figures are cause for concern since the proportion of Canadians over 65 is expected to increase from 11.7% in 1991 to 14.1% in 2011 (Moore and Rosenberg, 1997). This has implications for a variety of medical services in Canada already found to be under pressure from increased demand from older patients such as radiation oncology (Mackillop et al., 1994) and surgery to replace previous joint prostheses (Saleh et al., 1997). But in one area in particular, the elderly constitute virtually the entire demand: long-term care. In the United Kingdom (Monro, 1980), Australia (Lazarus and Gray, 1987), the United States (Swan et al., 1995), and Canada (Burkell et al., 1996) there are growing concerns about the ability to prioritize and accommodate an expanding elderly population in long-term care facilities. It seems reasonable to conclude that for a number of services an aging population creates heightened demand which may, in turn, create longer waiting lists.

3.7 Physician Factors

It is clear that physician behaviour has the potential to contribute to the development of waiting lists in several important ways. These include: pursuit of contrary priorities, disorganized practice environments, and clinical practice patterns.

Physicians lack incentives to align their practices with the goals of health bureaucrats or hospital administrators. For example, in the United Kingdom it has been argued that the costs of managing waiting lists efficiently - the goal of administrators - in terms of updating, prioritizing, rescheduling cancellations, computerizing and so on, are born chiefly by physicians through the added time and effort required. Conversely, the costs of inefficiency are born largely by patients (Culyer and Cullis, 1975). As well, it has been argued that a lengthy individual waiting list may actually be viewed as a testament to the special skills of a physician in comparison to colleagues in less demand, which may take priority over the well-documented efficiencies of shared waiting lists (Madhok, 1994). Finally, it has been argued that even in the state-funded system in Britain in subtle ways, for non-financial reasons, physicians induce demand for their services. They have an incentive to maintain long surgical lists, for example, to ensure a stock of available work, to guarantee a mix of cases for teaching purposes, or to assist in bargaining for additional hospital resources (Cullis and Jones, 1985).

The manner in which physicians organize their practices may influence list formation. It has been shown in the United States that patients wait longer for an appointment at a health maintenance organization than with a fee-for-service physician (Wolinsky and Marder, 1983). Somewhat paradoxically, in Finland shifting to a capitation system reduced long waiting lists for after-hours service which a fee-for-service system had been willing to gratify (Takala et al., 1997). Several United Kingdom studies have reported on the adverse effects which poor internal clinic organization or excess administrative tasks may have on the efficient flow of patients and the consequences that may have for escalation of waiting times (Duncan et al, 1988; Lal et al., 1990; Pope et al., 1991).

The patterns of clinical behaviour of physicians may contribute to the growth of waiting lists. Referrals by general practitioners can be directed away from consultants with long lists by informing the referring doctors of consultants with shorter lists (French et al., 1990). Consultants can reduce their outpatient lists by reducing the frequency of repeat patient visits (Davies et al., 1994). Close monitoring of waiting lists within individual institutions or regions may reveal physicians with significantly different thresholds for placing similar patients on waiting lists (Smith, 1994; Lundstrom et al., 1996). This may be a reflection of the

discrepancy between what clinicians state are appropriate prioritization criteria, and the more subjective criteria they have been found to deploy in practice (Iversen and Nord, 1992). In contrast to the subjective approach, when British physicians deliberately employ well-defined objective criteria for admission to a urology waiting list, the size of the list was substantially reduced (Barham et al., 1993; Schou et al., 1994).

3.8 Patient Factors

Patient factors exert an influence on the establishment and size of waiting lists. These factors may be grouped under three main headings: patient behaviour, social characteristics and clinical characteristics. Patient behaviour may be responsible in some cases for the length of lists and the time which individual patients spend on them. Patients may choose to remain on lists in order to see a specific physician (Fishbacher and Robertson, 1986) or to secure admission to a preferred long term care facility (Shapiro et al., 1992). They may also fail to cancel scheduled out-patient appointments or booked surgery (Houghton and Brodribb, 1989), which would have shortened waits for remaining patients. Finally, in the United Kingdom many patients are discovered during the auditing of waiting lists to no longer want surgery or to have received care elsewhere, but not to have removed their names from the list (Davidge et al., 1987).

Some patients may wait longer than others due to social, rather than clinical, characteristics. In Northern Ireland, being employed is a predictor of shortened waiting time for angioplasty (Gaffney and Kee, 1995). Patients from more affluent postal-code areas in a Montreal study were noted to experience slightly shorter delays in receiving hip fracture surgery (Hamilton et al., 1996). An American study demonstrated women undergo lung transplantation at a slower rate than males, though this may be reflective of problems matching smaller stature to larger donor organs (Sharples et al., 1994). Race has been said to influence receipt of kidney transplantation in the United States with blacks having longer waiting times (Eggers, 1995). Elsewhere, this has been disputed (Bryan, 1996; Ozminkowski et al., 1995). Race does not appear to explain differences in waiting times in American emergency rooms (Kilmarx et al., 1991). In Canada, admission to waiting lists for liver transplantation takes into account the amount of social support available to prospective patients (Mullen et al., 1996).

The clinical character of patients may contribute to the size of waiting lists and the duration of waiting times. Section 2.5 above discussed prioritization of patients according to subjective or objective perceptions of clinical urgency. However, there appear to be more subtle and less edifying ways in which patient clinical features may influence waiting time. It has been suggested in the United Kingdom that certain surgical conditions, usually associated with the elderly, are implicitly deemed unseemly and of little concern. Thus hernia repair, varicose vein stripping and haemorrhoid removal are covert diagnostic tickets to excessively long waits for admission (Frankel, 1989). Similarly, in the United States, hospitalized patients with emotional disorders and those with little prospect of improving with rehabilitation therapy have been shown to have longer waits for discharge to nursing homes than patients lacking these characteristics (Gruenberg and Willemain, 1982).

3.9 Changing Patterns of Disease

While passing reference is frequently made to the likelihood that changing patterns of disease may contribute to the generation or prolongation of waiting lists, there are no published studies which document this phenomenon. The assertion, however, seems entirely credible. The sudden appearance and wide dissemination of a serious new disorder such as AIDS might be expected to create, at least initially, queues for treatment and support programs. Similarly, alterations in the incidence of established diseases might also give rise to queuing. For example, cardiovascular disease death rates have been declining in Canada since the mid 1960s. This is thought to be due to reduced prevalence of smoking, a reduction in dietary fats, improved control of hypertension, and enhanced care of individuals with cardiovascular disease (Heart and Stroke Foundation, 1991). This enhanced care would, of course, include surgical care for which, despite the declining incidence, there are queues. The effective result of this declining cardiovascular mortality rate is that patients may survive to contract a malignancy. In Canada from the late 1960s to the mid-1980s the incidence of newly-diagnosed cancers and the number of cancer deaths increased yearly for both sexes (National Cancer Institute of Canada, 1996). A portion of the increase is independent of the aging of the population and the number of new cases is influenced by improved case registration and new methods permitting earlier detection (Belliveau and Gaudette, 1995). The significant increase in diagnosed malignancies, in turn, has put substantial pressure on Canadian treatment

facilities such as radiation oncology centres where waiting times have increased over the last decade to levels judged unacceptable by both Canadian and American physicians (Mackillop et al., 1995). Similar pressure has been noted in other jurisdictions such as Australia (Wigg, 1988).

3.10 Summary

This section has reviewed factors frequently cited as causing or contributing to the growth of waiting lists. The conclusions may be summarized as follows:

- ▶ Waiting lists are endemic to state-funded health care systems.
- ▶ Decentralized systems give rise to variation in the size of waiting lists and times waited across regions, institutions and physicians.
- ▶ The degree to which resource reduction influences lists is not uniform and may be mediated by local or individual circumstances.
- ▶ The deployment of technology may contribute to both the generation and the reduction of waiting lists.
- ▶ Population aging may be expected to create longer waiting lists for services used predominantly by seniors.
- ▶ Patterns of physician clinical and organizational behaviour may have a significant impact on list formation.
- ▶ Patient behaviour and characteristics may contribute to the growth of lists and the time spent waiting.
- ▶ Though poorly studied, changing patterns of disease likely contribute to the generation of some waiting lists.

4.0 Effects of Waiting Lists

4.1 Introduction

This section will review briefly the benefits claimed for waiting lists followed by consideration of the impact of waiting on patients and families, providers, and selected sectors of the broader health care system.

4.2 Waiting List Benefits

Though often out-weighed by disadvantages, some benefits to the health care system and individuals do result from waiting lists. In reference to the broad health system, waiting lists avoid the necessity of maintaining costly excess capacity. In the United States waiting is rare because this capacity is present, but the cost of such convenience is measured by the many Americans who can not afford to access health care. In publicly-funded systems such as those in Canada or the United Kingdom, waiting for elective services is the price to be paid for universal access to the system at no direct financial cost to the patient (Naylor and Slaughter, 1994).

Patients may derive benefit from waiting for treatment. They are given an opportunity to consider whether they actually wish to undergo proposed treatment. British studies of orthopaedic and urology waiting lists suggest when lists are audited between 17 and 31% of patients no longer wish surgery (Hochuli, 1988; Mobb et al, 1994). Waiting also confers the necessary time to make important financial, legal or domestic arrangements, particularly with reference to post-hospital care (Street and Duckett, 1996).

From a clinician's point of view waiting may have advantages as well. Some patients improve with "tincture of time" (Freeland and Curley, 1987) and the risks of treatment no longer are seen as being out-weighed by the benefits. Waiting also allows clinicians to rethink treatment options. New types of diagnostic tests, new treatment modalities, or simply better evidence as to the appropriate use of existing interventions may become available to redirect decision making. Finally, waiting lists, properly managed, offer physicians the opportunity to prioritize patients on the basis of clinical need, thereby ensuring the greatest benefit accrues from their treatment interventions.

4.3 Impact on Patients

Lengthy waits for medical services adversely effect patient quality of life. A Canadian study used two validated measures of health status to show that following hip or knee replacement patients experienced markedly less pain and role limitations than before surgery (Williams et al., 1997). Similar results were obtained in studies of United Kingdom patients awaiting orthopaedic surgery (Rigge, 1994; Roy and Hunter, 1996). The quality of life for urological patients awaiting transurethral surgery for benign prostate disease has been shown to improve following surgery (Hall and Hall, 1996), as has the self-assessed quality of life by heart transplant recipients compared to patients who remain on the waiting list (Rector et al., 1993). Referred to but seldom studied in detail (Higginson et al., 1992; Globerman, 1991) is the likelihood that the diminished quality of life for waiting patients may be associated with deteriorating economic circumstances. For example, a British study of patients awaiting orthopaedic surgery found one in eight patients had to give up employment due to symptoms (Rigge, 1994).

The degree of morbidity of patients awaiting medical treatment may increase. An Australian study found 25% of patients felt they had deteriorated while awaiting surgery and surgeons concurred with this belief in 14% of cases (Royal Australian College of Surgeons, 1991). In a British study, 50% of waiting surgical patients believed their clinical status had declined (West et al., 1991). The literature on this issue, however, is far from unanimous largely because most waiting lists are for elective patients whose condition is not expected to deteriorate precipitously. A British audit of an ophthalmology list discovered 10% suffered from conditions that had the potential to lead to irreversible visual loss (Lee et al., 1992). However, other researchers in the United Kingdom were unable to demonstrate any adverse consequences to delays in tonsil surgery (Freeland and Curley, 1987) or in urological surgery (Bishop, 1990). An extensive review of delays in the treatment of breast cancer provided no definite evidence on the consequences of delays once patients seek medical attention (Caplan and Helzlsouer, 1992/93).

Mortality is a well-defined outcome which has been studied in relationship to waiting times. A number of studies have focussed on transplantation surgery. In the United States the number

and proportion of patients dying while awaiting heart transplantation increased yearly from 1988 through 1990 (McManus et al., 1993), and a significant proportion of liver transplant candidates die before surgery (Gordon et al., 1991). Similar trends have been documented in Quebec for the period 1988 to 1992 (Carrier et al., 1994). The problem of waiting for transplantation is clouded, however, by the issue of donor availability as opposed to health care resource allocation questions. Though this is an area awaiting public policy development to enhance organ retrieval rates, it is beyond the scope of this report.

A more appropriate area to review is the relationship between mortality and waiting for coronary bypass surgery. A Manitoba study of six years of administrative data concluded that urgent cardiac cases received expeditious surgery, while non-urgent cases who waited showed no increased risk of death (Hartford et al., 1995). A similar conclusion was reached concerning the Manitoba experience with waiting for cardiac catheterization (Morris et al., 1990). An Ontario study reviewed the experience for 8,517 consecutive coronary bypass patients following the establishment of a provincial patient registry in 1991. While in the queue 31 patients (0.4%) died and 3 had surgery deferred after nonfatal myocardial infarction (Naylor et al., 1995). A Halifax study of all patients referred for bypass from Nova Scotia and Prince Edward Island in a seven month period reported a 1.2% mortality rate, spread evenly across four categories of urgency (Cox et al., 1996). A Montreal group reported no effect of waiting on mortality for elective open-heart surgery (bypass, valve replacement, or both) for a series of 568 patients (Carrier et al., 1993). These results are generally similar to those reported for Europe (Bernstein et al., 1995; Suttorp et al., 1992; Bengtson, 1996) and New Zealand (Doogue, 1997).

It appears that waiting time for cardiac surgery, potentially one of the most dangerous of medical waits, does not significantly alter mortality risk. This may reflect an increasingly sophisticated ability to triage patients and manage their waits so as to avoid fatal outcomes (Maziak et al., 1996). Only waiting times for the treatment of potentially curable malignancies might be expected to show an equally important link with mortality. While the literature makes clear that Canadian waiting times for radiation oncology are inappropriate by international standards (Mackillop et al., 1995), the precise impact on clinical outcomes remains uncertain.

The impact of waiting on patients must be considered in terms other than mortality and morbidity; it also influences the emotional states of patients and their families. Canadian patients awaiting an opportunity for cardiac bypass surgery display increased levels of anxiety (Wright and Arthur, 1996) and fear (Rakoczy, 1977). Patients in the United Kingdom on bypass lists were found to display high levels of anxiety, depression, and impairment of work and family relationships which correlated significantly with time spent on the list (Underwood et al., 1993). Swedish patients awaiting bypass display similar levels of anxiety as well as increased insomnia, use of sedatives, and tobacco abuse (Bengtson et al., 1994). Emotional difficulties are also noted in patients awaiting transplantation (Hirth and Stewart, 1994), and an American study has documented the negative effects waiting has on spouses of transplant candidates (Collins et al., 1996). It should be noted, however, despite the emotional turmoil of waiting, the vast majority of Canadian patients undergoing coronary bypass (96%) have been found to consider the process of queuing by medical need to be fair (Petrie et al., 1996) and a similar percentage (93.2%) of patients receiving knee replacement found their waits acceptable (Ho et al., 1994).

Waiting times may influence the manner in which patients interact with the formal health care system which, in turn, may exert adverse effects on both the patient and the system. For example, a significant correlation has been found between the length of waiting time and failure to attend initial appointments (Stern and Brown, 1994). The patient is deprived of a possibly necessary service and the system is left with an empty appointment slot which could have gone to another patient. Similarly, patients may attempt to speed their access to a scarce service by keeping their names on the referral list of more than one specialist or facility at a time, thereby inflating perceptions of the number of patients waiting. Some patients may tolerate troublesome but correctable symptoms because the length of waiting lists discourages them from seeking treatment. Finally, patients may receive treatment in another location without removing their names from waiting lists.

In summary, waiting lists adversely affect patients' quality of life, induce emotional upset in patients and relatives, have been shown to have a minor effect on morbidity, and have scant documented effect on mortality.

4.4 Impact on Providers

There is very little well-documented information about the impact of waiting lists on physicians and none on other important providers such as nurses or hospital administrators. The assertion is made that physicians may actually cultivate long waiting lists as a sign of prestige amongst colleagues and so as to assure a readily available pool of patients. However, it seems likely that the predominant effect of waiting lists on providers, as in the case of patients, is negative.

Waiting lists are a source of frustration to physicians who feel themselves deprived of the tools and ability to deliver clinical care in an optimal fashion (Katz et al, 1991). For some it is sufficient reason to re-locate to the American practice environment in which waiting is seldom encountered. Those who remain may face the prospect of watching what they view as the deterioration of patients while awaiting care. This is difficult to justify as a health care provider and may also raise issues of medico-legal liability (Naylor, 1991). Moreover, physicians are uncomfortable with the ethically ambivalent role into which, as a profession, they have unwittingly been cast. On the one hand they are expected to act as the patient's advocate, while on the other, they are expected to ration scarce health resources on behalf of a constrained system (Azevedo, 1993; Cox, 1994). This discomfort may explain why physicians, reputed as a group to resent any intrusions on individual clinical autonomy, have, in fact, welcomed objective systems of clinical prioritization. Physicians in both Ontario and New Zealand have readily adapted to centralized systems to allocate coronary bypass on the basis of documented clinical need (Naylor et al, 1992b; Hadorn and Holmes, 1997b). For doctors, as for their patients, waiting lists exert a negative impact.

4.5 Impact on the Health Care System

Waiting lists have the capacity to influence adversely public perceptions of and confidence in the health care system. For example, polling in 1997 suggested a slow but steady increase in the number of Canadians who believe waiting times for services such as surgery or emergency room care are increasing largely due to inadequate funding (Angus Reid Group, 1997). Such perceptions are influenced by media reporting of apparent deficiencies in the system (Naylor, 1991; Azevedo, 1993; Katz et al., 1991), a phenomenon poorly documented but apparently

noted also in Australia (Street and Duckett, 1996) and the United Kingdom (Bloom and Fendrick, 1987). This type of adverse publicity may serve a useful role by motivating politicians to focus their attention on issues of health care access and by compelling bureaucrats to give priority to areas beleaguered by inordinate waits (Jacobs and Hart, 1990).

Waiting lists influence more than public perceptions and politicians; they also may make an important impact on the costs of the health care system in three different ways. First, waiting lists allow the health system to control costs through non-price rationing, while continuing to provide the service in question. That is, costs may be kept stable by choosing, in the face of rising demand, not to increase resource inputs, but rather, to let waiting times increase. Secondly, waiting lists may increase the costs to the economy by keeping some citizens waiting in a state of health incompatible with productive employment (Nord, 1990; Kingsley, 1988). The magnitude of this cost is uncertain, but a Canadian study has estimated the lost productivity to be in the same range as that due to labour disputes (Globerman, 1991). As well, there are additional costs to the health system associated with the delay of treatment of patients who have deteriorated while awaiting care (Saleh et al., 1997). Finally, in certain circumstances the costs of non-essential aspects of the publicly-funded health care system may be reduced by cutting service substantially, allowing the development of waiting lists, and transferring the bulk of the service to the private sector. Services such as outpatient dietitian counselling for obesity, once available in many Ontario hospitals, appears now to be largely a privately-purchased service. This does not decrease and likely increases over-all health care expenditures.

Waiting lists may influence the health care system in a third important area: resource allocation. Growing waiting lists may act as a warning flag that a demand and supply mismatch is evolving for a particular service. This was the case in Ontario in the case of access to coronary artery bypass surgery in the late 1980s (Kaminski, et al., 1989; Naylor et al., 1993). Escalating waiting times may be of use to hospital administrators or regional authorities as a bargaining chip in the quest for enhanced resources from provincial governments. Finally, the existence of lengthy lists for a specific service in a particular region may redirect the flow of patients in new and unanticipated ways which creates pressure on

substitute services or the resources of contiguous regions.

Waiting lists, then, may exert an impact on the reputation, costs and patterns of utilization of the health care system.

4.6 Summary

Waiting lists may confer minor benefits on providers and patients, but these advantages are out-weighed by adverse effects. Waiting may exert a detrimental effect on patients' quality of life, induce emotional upset in family and friends, exert a minor effect on morbidity, and produce a negligible effect on mortality. Waiting lists produce frustration for providers who can not provide what they view as expeditious care, and force upon them the unpleasant task of deciding to whom scarce resources should be allocated. Finally, lengthy waiting lists detract from confidence in the health care system, as well as increasing costs and fostering alterations in patterns of utilization.

5.0 Additional Issues

5.1 Introduction

The preceding sections have discussed the definition, causes, and effects of waiting lists. The following section focuses on several important issues not captured in the above discussion including: the relationship between waiting lists and need; the influence of waiting on reasonable access to medical services; the impact of increased resources on waiting times; the link between waiting lists and privately-financed medical services; and methods available to determine appropriateness of waiting times.

5.2 Waiting Lists and Health Needs

There is debate as to whether waiting lists can be taken as legitimate reflections of need for health care services. The existing evidence suggests there is limited correlation between need and waiting.

Waiting lists do not represent accurately persons within a defined population who need a specific service. As previously discussed (Section 4.14), lists when audited are found to include the names of many patients who no longer wish or require the service in question (Hochuli, 1988; Roy and Hunter, 1996). Secondly, there is concern that there is substantial variation amongst physicians in the criteria used to undertake procedures (Naylor and Jaglal, 1993) or place patients on waiting lists for procedures or investigations. In the case of cataract surgery, for example, some patients may be entered on the list well in advance of surgical need in anticipation of possible progression to need while on the list. Thirdly, there is concern that growing waiting lists for outpatient specialty consultation may reflect inappropriate referral behaviour by family physicians rather than increasing need. One British study has examined this issue and found no evidence of an increase in inappropriate otolaryngology referrals when a two month period in 1981 was compared to a similar period in 1989 (Nunez, 1993). Finally, in the United Kingdom it is considered likely that some patients with legitimate need are either deterred from seeking care or their family physicians are discouraged from making referrals due to lengthy waiting lists (George et al, 1983). Waiting lists, then, may both over- and under-estimate need.

It appears likely that most waiting lists fail to prioritize explicitly patients on the basis of need. There are, of course, exceptions, as in the case of the Ontario registry of patients awaiting coronary bypass surgery. But if need is taken to mean the ability to benefit from a service, the lists kept by multiple independent practitioners and facilities are not capable of ranking patients by this criteria for a given catchment area. Thus, an individual with no co-morbidities which would inhibit the ability to rehabilitate following a surgical intervention, has no guarantee of priority over another patient with co-morbidities likely to influence rehabilitation adversely.

If waiting lists do not accurately reflect unmet health care *need*, they may reflect unmet *demand* in a given community. It is important, however, to introduce a caveat. The extensive literature on the concept of supplier-induced demand (e.g., Evans, 1974; Labelle et al., 1993) suggests that at least a portion of the demand captured on waiting lists reflects physician rather than patient interests (cf. Globerman, 1991). That is, if as well versed in the requisite

area of medical knowledge as their doctors, some patients would choose not to demand the service. Waiting lists, then, do not necessarily reflect either needs or patient demand.

5.3 Waiting Lists and Equity of Access

In the United Kingdom there is concern that waiting lists prevent access to medical services. A subset of patients with conditions deemed of little medical interest appear to be consigned to a *mortlake* of perpetual waiting with little hope of actually accessing the desired service (Frankel, 1989). In Canada there is no reported evidence of such stagnant pools of waiting patients; access may be significantly impeded, but not completely denied.

On a national level, as discussed above (Section 3.2), waiting lists are associated with the universal accessibility of publicly-funded systems and not with entrepreneurial systems which ration access according to the ability to pay. Hence, the existence of waiting lists may signify on the part of the system at least a theoretical commitment to equity of access to services. That the commitment remains theoretical, however, is the result of organizational characteristics found at the sub-national or local level. Indeed, most access problems arise because independent lists are kept by individual physicians or institutions. The size of and admission criteria to lists vary substantially between and within provinces and regions, allowing some patients with lesser need to supercede some with greater relative need in the queue for service access. Depending on the manner in which they are deployed, then, lists may enhance or detract from the equitable access to health care on the basis of relative need.

5.4 Waiting Lists and Resource Augmentation

Lengthy waiting lists may give rise to suggestions that additional resources would reduce waiting times. Ontario's successful attack on coronary artery bypass queues in 1989-90, for example, combined organizational changes with enhanced resources (Naylor, 1991). There are other examples from the United Kingdom of successful reductions in waiting times after an infusion of additional financing. In the case of general surgery (Parmar, 1993; Harvey et al., 1993), ophthalmology (Lee et al., 1992), and urology (Mobb et al., 1994) list audits combined with additional dedicated surgical resources appeared to reduce lists within limited follow-up periods.

Many other attempts at reducing waiting lists by adding resources do not appear to have succeeded. A British study of an attempt to reduce an orthopaedics waiting list by adding weekend surgery found the list remained static (Mackinnon et al., 1992). In general surgery an initiative targeting patients who had endured a lengthy wait did, indeed, reduce long waits, but compromised access for patients with potentially more serious conditions who had not yet experienced long waits (Umeh et al., 1994). One-time investments to reduce waiting may result in improvements which prove transient, as shown by a British study of an ophthalmology initiative (Storow et al., 1989) and a large Swedish study of a variety of surgical procedures (Hanning, 1996). Nor is this lack of improvement confined to surgery. Studies of long-term care waiting lists in the United States (Gruenberg and Willemain, 1982; Falcone et al., 1991), and Australia (Lazarus and Gray, 1987) suggest that additional beds will do little to resolve the waiting problem.

Far from reliably reducing the size of waiting lists, extra resources in the United Kingdom may well have the opposite effect. A study of several surgical services in the Oxford area found that as the number of hospital admissions from the list increased so, too, did the length of the waiting list (Goldacre et al., 1987). This phenomenon has been referred to as “feedback” and describes the tendency of family physicians to preferentially increase referrals to services which appear to have shrinking waiting lists, thereby off-setting any gains (Worthington, 1987). As well, adding surgeons to a hospital may initially reduce pre-existing lists but by the same mechanism will, within two years, spawn new lists (Frost, 1980). Hospital-based physicians, it has been argued, have no real incentives to cut waiting lists (Cullis and Jones, 1983) and in the face of new resources may reassess what “needs” to be treated, thus lengthening lists rather than reducing them (Culyer and Cullis, 1975). An Australian study notes that hospital managers who receive extra resources to deal with long waiting lists have little incentive to reduce lists if they appeared to be rewarded with augmented resources (Street and Duckett, 1996). Finally, an American study has suggested that exceeding a hospital bed occupancy rate of approximately 70% will result in the initiation of waiting lists; at rates beyond 90% the rate of growth in lists is described as precipitous (McQuarrie, 1983).

This brief review of the relationship between waiting lists and enhanced resources suggests that it is by no means axiomatic that additional resources will reduce waiting times. In certain cases in which funding has diminished in comparison to clearly defined need, extra resources appropriately organized will assist in reducing waiting times. In many other circumstances such resources are unlikely to have a significant impact on waiting times and in some instances may actually exacerbate the length of the waiting lists.

5.5 Waiting Lists and Private Care

It is frequently suggested that the option of privately purchasing medical services would reduce waiting in the public sector. This does not appear to have occurred in the United Kingdom despite the option of “going private” which is exercised by 13% of the population (Richmond, 1996). Approximately 20% of non-urgent heart surgery is done privately, a figure comparable to that in New Zealand (Dooge et al, 1997). The bulk of private surgical work focuses on hips, hernias, haemorrhoids, cataracts and gynaecology. These are some of the conditions with the longest waiting times in the public sector and, indeed, the areas in Britain with the longest waiting lists have the highest rates of private surgery. There is concern that this link reflects the ability of surgeons who maintain long waiting lists to encourage better-off patients to jump queue and pay for elective surgery privately (Bloom and Fendrick, 1987). Despite regulations that limit the amount of private medical income to 10%, this policy is neither adhered to nor enforced (Richmond, 1996). Many other factors, of course, influence the decision to pay for care including the price of private care, the anticipated length of the wait, the nature of the clinical condition, and macro economic indicators such as interest rates or the consumer price index (Goddard et al., 1995).

In Canada it is generally not possible to purchase privately those treatment or diagnostic services for which significant queuing exists. Some patients may seek treatment in the United States privately, and provincial governments in times of acute shortage may contract with American providers (Azevedo, 1993; Katz et al., 1991). In the United Kingdom it has been suggested that the public system could subsidize patients seeking private care up to the current cost of public care (Cullis and Jones, 1983; Cullis and Jones, 1985). This is similar to a model of publicly-financed competition for primary care discussed for Canada (Muldoon and

Stoddart, 1989; Muldoon, 1991). It is doubtful such options will find acceptance by a Canadian public who cherish a universal, publicly-funded system. For example, when Manitoba cataract patients were surveyed after surgery only 15% responded that they would be willing to pay for private care or to pay increased taxes to guarantee more rapid access to the public system (Anderson et al, 1997). Similarly, Canadian knee-replacement patients, though waiting longer than American recipients, found waiting times acceptable in over 85% of cases surveyed (Ho et al, 1994; Coyte, 1994). The willingness to accept current waits and the unwillingness to pay for alternatives, suggests there is little room for policies designed to encourage a private alternative to publicly-funded care in Canada.

5.6 Setting Appropriate Waiting Times

Deciding what constitutes excessive waiting is by no means a straightforward task. The following methods are among the options for making such decisions:

- ▶ **Government standards:** In Sweden, Norway, Denmark and the United Kingdom government has established guaranteed waiting times for specific procedures and has provided financial incentives for providers to achieve these levels. The precise mechanisms by which the target times are selected is not clear, but may reflect a subjective assessment of what is “reasonable”, coupled with what is deemed achievable (Hanning, 1996).
- ▶ **Stakeholder opinion:** It is possible to survey patients (Petrie et al., 1996), hospital administrators (Jacobs and Hart, 1990), consultants, and referring physicians (Clover et al., 1996) as to their views of appropriate waiting times.
- ▶ **Clinical criteria:** Maximum waiting times may be defined according to clinical criteria in two general ways:
 - *expert opinion* - in the absence of objective, established standards it may be necessary to seek a consensus from experts in the field. This was the approach used in Ontario to initiate the provincial program for coronary artery surgery

(Naylor et al., 1991) and has also been used for the same purpose in New Zealand (Hadorn and Holmes, 1997b).

- *clinical evidence* - The clinical consequences of delay may be monitored so as to determine limits within which patient safety is not compromised. This approach to matching urgency classification with time guidelines was used in Alberta by the Provincial Advisory Committee on Cardiovascular Services. It tracked patients for a 3-year period and adjusted guidelines after documenting that median waiting time to adverse events occurred much earlier than expected (Kieser et al., 1995). As well, validated instruments exist which can be used to assess objectively non-life-threatening aspects of waiting, such as pain and social functioning, from which to derive thresholds for timely intervention (Williams et al., 1997). Finally, simulations of the biological events in the chronology of a disease process may be created to determine the window of safety for delaying treatment. This approach has been used in radiation oncology to predict the effect of delay on local control of malignancies (Mackillop et al., 1996).

5.7 Summary

This section has established that waiting lists are a poor indicator of health need. They exert a variable impact on equity of access to health care and generally do not respond to enhanced resources in a predictable fashion. Long waits do not appear to create increased receptivity to private care on the part of Canadian patients. Finally, a variety of methods are available by which an iterative process of appropriate waiting time estimates may be initiated.

6.0 Precis to the Report

The forgoing overview has provided a background and context for the development of the survey instruments and questionnaires which form the basis of the analyses to be found in the next three chapters. A more detailed critical review of this and other literature is presented in chapter 5. The information from the literature and individual studies will be summarized in a concluding policy commentary.

Chapter 2:

Waiting for Medical Services in Canada: A Survey of Attitudes and Activities of Provincial and Territorial Governments

**S.E.D.Shortt
Paul McDonald
Claudia Sanmartin
Morris Barer
Steven Lewis
Sam Sheps**

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EXECUTIVE SUMMARY

A semi-structured interview was administered to key informants in provincial and territorial ministries of health. Ten of twelve jurisdictions chose to participate.

Significant findings included the following:

- ▶ the services for which waiting was a concern included: orthopaedic surgery, cardiac surgery, ophthalmology surgery, magnetic resonance imaging (MRI), out-patient mental health services, and cancer care
- ▶ with the exception of cardiac surgery in two provinces, no province or territory actively participated in the supervision of waiting lists
- ▶ two provinces have published waiting times studies, while four have completed focussed internal studies
- ▶ most jurisdictions complained of a lack of adequate data and benchmarks for appropriate waiting times
- ▶ the major causes of waiting lists were seen as inadequate resources, lack of coordination and changes in demand due to population aging, technology and changes in treatments
- ▶ all respondents stated there was no evidence of adverse health outcomes from waiting in their jurisdictions
- ▶ there was no agreement as to the single best method to define appropriate waiting times, though clinical evidence and public opinion were both seen as important
- ▶ there was no firm consensus on the importance of waiting issues

1.0 Introduction

Waiting times for some medical services appear to be an issue of growing concern in Canada. The media is quick to report the largely unfavourable picture of service access painted by the annual Fraser Institute report on waiting lists (Ramsay and Walker, 1997). An increasing proportion of the public, according to an Angus Reid poll in late 1997, believes surgical waiting times are becoming longer (Angus Reid Group, 1997). A recent survey of Calgary family physicians revealed that 92% believed their patients experienced excessively long waits before being seen by specialists (Walker, 1998). Despite such public views, however, there is little or no information available on how this issue is viewed within provincial and territorial governments - are waiting times an area of major operational concern or policy priority? The purpose of the following chapter is to explore the attitudes and activities of provincial and territorial governments related to waiting times and waiting lists for medical services in their respective jurisdictions.

2.0 Objectives

This study describes:

- ▶ past, present and future activities on the part of provincial and territorial governments in reference to waiting times/lists for medical services
- ▶ attitudes towards and opinions about key waiting list/time issues

3.0 Study Design

- ▶ semi-structured telephone interviews

4.0 Subjects

An appropriate respondent for each jurisdiction was selected in consultation with individual provincial and territorial ministry of health officials.

5.0 Method

An interview instrument [Appendix 2.A] was developed by researchers from Queen's University Health Policy Research Unit, the Saskatchewan Health Services Utilization and Research Commission, and the University of British Columbia Centre for Health Services and Policy Research.

The questionnaire was designed to elicit information in three broad areas:

- ▶ the extent, nature and management of lists in each jurisdiction (Q 1 to 4, 6, 7)
- ▶ perceptions of the purpose, causes, effects and importance of waiting lists (Q 5, 8 to 12, 17, 18).
- ▶ actions taken or planned, and constraints upon such actions (Q 13 to 16, 19)

Two additional questions (20, 21) were asked to assist in identifying other essential respondents and significant published material from each jurisdiction.

The instrument was faxed to the provincial or territorial respondents and a time scheduled in which to conduct the interview. Providing the questionnaire in advance allowed the respondent to confirm that she/he was, indeed, the individual in that jurisdiction best suited to answer the questions, to prepare by gathering relevant information or consulting with colleagues, and to vet questions to allay concerns about speaking on behalf of their government on a potentially contentious issue.

The questionnaire was administered by telephone one to two weeks after the initial contact. Three interviewers participated in the project, and interviews ranged in length from 45 to 90 minutes. All interviews took place in February and March, 1998.

6.0 Results

6.1 Response Rate

Ten of twelve provincial and territorial governments identified respondents who participated in the interviews. Despite repeated contact, Manitoba and Quebec were unable to nominate respondents.

6.2 Areas of Most Concern

Respondents tended to identify a core of similar services as areas of concern, as well as other services specific to their own region. The frequency with which respondents mentioned specific services is displayed in Table 2.1.

Table 2. 1: Frequency Ranking of Services for which Waiting is a Concern

orthopaedic surgery	7	general surgery	1
cardiac surgery	5	otolaryngology surgery	1
magnetic resonance imaging	5	endoscopy	1
out-patient mental health	4	emergency room admissions	1
ophthalmology surgery	3	remote area physicians	1
cancer care	2	long term care	1
all elective surgery	1	out-patient physiotherapy	1

6.3 Maintenance of Waiting Lists

With the exception of Ontario and Nova Scotia, which took an active role in ensuring cardiac surgery was effectively managed, none of the provinces or territories actively manage waiting lists for any clinical service. Most provinces track waiting times for some services, but data are actually collected by regional health authorities. Waiting lists, excepting only cardiac surgery, are created and maintained by individual physicians, diagnostic facilities, or institutions. Despite this decentralized approach, five of the seven respondents who were able to answer the question, felt

this method of list creation was acceptable. Waiting times were considered by 7 of 10 respondents to be in general the same or less than three years ago.

6.4 Waiting List Initiatives

Of the 10 respondents, five reported that their jurisdictions had reacted to increased waiting lists for specific services by targeted enhancement of funding for the problem areas. Three respondents mentioned active efforts to collect improved waiting time data. Initiatives planned for the future included enhanced data collection, plans to define appropriate waiting times, and attempts to educate the public and providers as to reasonable expectations. No studies of waiting issues had been undertaken by 4 of 10 jurisdictions, 4 had completed internal studies of specific services, and Nova Scotia and British Columbia had published studies of surgical waiting times. Most respondents indicated a need for uniform, accurate data on waiting times in their province or territory as well as a need for evidence-based information on what length of time constituted an acceptable wait for each clinical condition. Constraints on effective policy making included a paucity of reliable data on waiting times, a lack of objective criteria by which to define excessive waits, inadequate provincial and territorial governmental resources to permit appropriate tracking of waiting issues, physician financial disincentives to co-operate in reducing waiting lists, and inappropriate political and media influence on policy decisions.

6.5 Purpose of Waiting Lists

Most respondents indicated waiting lists were a mechanism by which to allocate scarce resources, and several also indicated that such lists were a means to monitor the performance of the health care system. Respondents generally were unable to estimate how well lists performed these roles.

6.6 Causes of Waiting Lists

A majority of respondents emphasized scarce resources as a major cause of waiting lists, with lack of coordination of existing resources and increased demand due to an aging population, new technologies and shifting treatment tactics also receiving frequent mention. Respondents were asked to comment on several specific relationships summarized in Table 2.2.

Table 2.2: Factors Influencing Waiting Lists

Factor	Increase	Decrease	Static; unknown
hospital restructuring	2	2	6
regionalization	2	3	5
personnel resources	9	0	1
private care	1	4	5
physician payment method	1	0	9
technology access	6	2	2
aging population	9	0	1
disease shifts	3	0	7
patient behaviour	8	0	2
physician decision-making	5	0	5

From the table it can be seen that only three factors - the availability of health care personnel, an aging population, and patient behaviour (largely demands for inappropriate referrals or investigations) - were deemed to have a strong positive relationship with waiting lists.

Interestingly, four of ten respondents felt that increased availability of private care would serve to reduce waiting lists and most respondents saw no relationship between method of physician payment and waiting lists.

6.7 Results of Waiting Lists

All respondents identified patients and their families as those most affected by the existence of waiting lists. Many, however, also noted that long lists posed problems for a range of health care providers and for governments forced to confront consumer displeasure. All respondents stated that in their jurisdiction waiting lists did not inhibit access to medically necessary services.

Further, respondents agreed that there was no evidence of significant adverse health outcomes as a result of patients waiting for treatment. For a number of respondents, the most adverse outcome identified appeared to be the unfavourable publicity associated with lengthy waits which detracted

from the reputation of the health care system and created political fallout for politicians of the day.

6.8 Defining Appropriate Waits

There was little clear consensus as to how appropriate waiting times might best be defined. Clinical criteria which estimate the risk of deterioration in health status were cited as important by 6 of 10 respondents. Complaints from the public or providers were seen by 4 of 10 interviewees as important signs of inappropriate waits. Finally, several respondents felt that waiting times could be compared across jurisdictions to derive reasonable benchmarks..

6.9 Importance of Waiting Times

There was considerable divergence of opinion as to the importance of waiting times to provincial and territorial health authorities. One respondent considered waiting lists/times the most important issue on the provincial health care agenda, two felt it was very important, and two saw it as simply important, along with many other issues. However, 5 of 10 respondents did not feel waiting times were a major issue, viewing them as less important than other issues such as regionalization or cancer care, or as little more than a barometer for the performance of more fundamental aspects of the health care system.

7.0 Limitations

This study suffers from at least three limitations. First, 2 of 12 jurisdictions failed to participate in the interviews. It is possible that provinces or territories with significant waiting problems would refuse participation, thereby providing at best an incomplete, and at worst a misleading overview of jurisdictional views. Alternatively, the non-participants may view waiting times as an insignificant issue. Secondly, the individual respondents may not have been able to represent fully the views of their own ministries. There appeared to be a bias in favour of interviewees associated with acute care services, with a corresponding neglect of informants well-versed in mental health services or long term care. Most current waiting issues, however, appear related to acute care,

especially surgery. Thirdly, the interviews were done by three researchers which may have introduced some inconsistencies in posing questions or recording responses. Since all researchers participated in the construction of the interview instrument, however, the intent of each question was clear to the interviewers. This ensured a uniform manner of presenting the questions to the subjects. As well, the results were analysed and the report was written by one researcher in order to minimize inconsistent interpretation of results. In general, therefore, the results are likely to be an accurate reflection of the views of at least ten provincial and territorial governments on the issue of waiting lists and times.

8.0 Discussion

This survey of provincial and territorial governments suggests they are engaged in relatively little activity directly related to waiting issues. This may simply reflect the fact that waiting lists are compiled almost exclusively in the offices of individual physicians, diagnostic facilities, or hospitals. Provincial governments, therefore, lack centralized data from which to identify problems or craft solutions. Were this the only explanation for limited activity, however, evidence might have been found of concerted efforts to gather reliable data. Yet such efforts appear at best sporadic.

Another reason for limited activity may be found in the lack of consensus on the importance of waiting issues. Until relatively recently for most services, in most areas of Canada, waiting was not seen as a significant problem. Indeed, even now, the list of services for which there is agreement that waiting is said to pose difficulties is confined to half a dozen items. It may simply be that the issue of waiting is not a significant inclusion on the health policy agenda.

A third explanation for the current lack of activity in the area of waiting lists/times may be that the status quo is deemed satisfactory. That is, respondents may understand the manner in which patients come to be placed on lists, are familiar with the literature in this area, and accept the political dynamics of the issue.

Within the limited provincial activities to date there is no clear evidence of a long-term commitment to monitoring and responding to waiting times. Instead, most actions appear to be targeted, short-term interventions to react to specific service situations which are deemed to have become clinically or politically unacceptable. These responses usually involve an infusion of resources to expand existing programs.

These actions may reflect a limited theoretical understanding of waiting issues. For example, the literature on resource enhancement as a long-term solution to lengthy waiting times suggests a lack of efficacy in most cases. As well, there is no clearly articulated strategy by which to define appropriate waiting times, though useful suggestions may be found in the existing literature (see above, chapter 1). It appears that the provincial approach to waiting times is highly pragmatic and confined to a few well-publicized services.

There was, however, a belief among a majority of provincial and territorial respondents that the services currently suffering most from a waiting time problem included: hip and knee replacement, cardiac surgery, MRI, out-patient mental health services, cataract surgery and cancer care. There is also a shared concern that the aging of the population plays a significant role in augmenting demand for this particular list of services, and may be expected to do so over the next two decades.

Finally, there is a congruence between the favoured explanation for growing waiting lists, a lack of resources, and the most common intervention, enhanced funding. There may be cases in which this is the most appropriate diagnosis and treatment for excessive waits. But this should not lead to the facile assumption that the approach will succeed in all cases. Rather, a variety of strategies designed for the long-term, such as improved data collection, coordinated lists, centralized resource booking, and evidence-based clinical criteria governing when patients are placed on lists and how they are prioritized, must be initiated.

9.0 Conclusion

This study has demonstrated that provinces and territories have identified similar service “hot spots” for which waiting times appear to be a growing problem. Resource constraints were identified as the leading cause of lengthy waiting lists, and there was unanimity that to date there has been no evidence of adverse clinical outcomes associated with waiting. There is significantly less consensus as to how appropriate waiting times should be defined, or, indeed, how significant waiting issues actually are for the provision of equitable access to quality health care. Perhaps reflecting the latter confusion, most jurisdictions did not actively manage any waiting lists and few had undertaken extensive studies of the phenomenon. However, most jurisdictions did indicate a desire to collect more data and to participate in the establishment of reasonable definitions of appropriate waiting times. In summary, waiting issues appear to be a relatively new item on the Canadian health policy agenda. Provincial and territorial governments are only now beginning to acknowledge this, largely in reaction to the appearance of “hot spots” identified by clinicians and institutions directly or through the media. There appeared to be relatively limited understanding in most territories and provinces of the nature of lists (how they are created, maintained and used), the determinants of waiting times, and the effects of particular policy approaches on waiting lists and waiting times.

APPENDIX 2.A
Provincial Interview :Waiting Times / Waiting Lists

Date:
Interviewer:
Ministry:
Contact for Interview:
Comments
.....
.....
.....

Introduction

My name is I am a researcher at..... My group, and two other research units elsewhere in Canada, has been contracted on behalf of Health Canada to assemble information about waiting times and waiting lists for medical services. The importance of conducting this research has been endorsed by the Canadian Health Care Association and the Canadian Nurses Association.

We have created a list of key contacts in provincial ministries of health whom we believe may help us in this task. You are one of those we have identified as a contact person.

We would appreciate your participation in our 30-minute telephone interview.

We will send you an executive summary of our findings. More detailed results will be made available after April 17 on the web site of the Saskatchewan Health Services Utilization and Research Commission at :

<http://www.sdh.sk.ca/hsurc/> (choose "Utilization Research").

Question 1.

Are waiting times or waiting lists for medical services (medical/surgical treatment, diagnostic investigations, mental health services) a concern in your province and, if so, for what services ?

Question 2.

Do you believe there is more, less, or about the same amount of queuing for the services of concern to your ministry than was the case three years ago?

Question 3.

Does your province actively manage any waiting lists and, if so, for what services and how were they chosen?

Question 4.

Is the active management of waiting lists the formal responsibility of any other groups in your province?

Question 5.

In the Canadian health care system what is the basic purpose of waiting lists and how well do they

accomplish this role?

Question 6.

How are the lists you have mentioned are 1)defined, 2)created, and 3)managed?

Question 7.

Is this methodology appropriate or can you suggest preferable methods?

Question 8.

Are you aware of any negative outcomes from the existence of waiting lists in this province and, if so, how has your ministry responded?

Question 9.

What do you believe are the major causes of waiting lists in order of importance? (For example, inadequate resources, lack of co-ordination, changing demographics, altered disease patterns?)

Question 10.

Would you comment on your ministry's view of the relationship -if any- between waiting times and the following factors:

1. institutional restructuring
2. regionalization
3. regional variation in access to services
4. health care personnel availability and mix
5. privately-funded care
6. physician payment formats
7. access to technology
8. population aging
9. changes in disease prevalence/incidence
10. patient behaviour and preferences
11. the appropriateness of thresholds for treatment/investigation

Question 11.

Broadly defined, who is effected by waiting for medical services and how?

Question 12.

How should we decide if waiting times are excessive and does your ministry have a system for identifying excess waits?

Question 13.

Has your ministry undertaken any initiatives in the last five years to deal with waiting times and, if so, in what areas, how, and with what results? Can you provide a contact name?

Question 14.

Does your ministry have suggestions for future policy options to deal with issues concerning waiting times?

Question 15.

Does your ministry perceive any impediments to effective policy formation in this area?

Question 16.

What specific data or information would be of use to your ministry for policy formation purposes?

Question 17.

Do waiting lists inhibit your provinces ability to provide services which would generally be deemed “medically necessary”, and if so, please give specific examples.

Question 18.

Taking into consideration the various issues in health care today, how important is the issue of waiting times and lists? Can you give examples of issues your ministry considers more important?

Question 19.

Is or has your province produced any studies of or position papers on waiting-related issues? If so, would you be willing to share them with us?

Question 20.

Is there anyone else you feel we should talk to either in your ministry or beyond?

Question 21.

Do you have any additional information or comments you would like us to have?

Conclusion

We appreciate your help and that of your Ministry. Please feel free to contact us at any time if you have additional information for us or believe that we may be of assistance to you.

Chapter 3:

Availability, Uses, and Perceptions Of Health Service Waiting Lists Within Canadian Hospitals, Regional Health Authorities, and Cancer Organizations

**Paul McDonald
Steven Lewis
Glen Andre
Mark Kelly
Morris Barer
Sam Shortt
Sam Sheps
Claudia Sanmartin**

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1.0 Introduction

Although waiting lists have been popularly described as a threat to the health care system, it has been also been argued that, when properly constructed and managed, precisely the opposite may be true (Amoko, Modrow & Tan, 1992; Hadorn & Holmes, 1997; Naylor, 1991). This latter position is based on the notion that waiting lists make it easier to plan and allocate resources fairly because they provide some predictability in types and volumes of services provided. In addition, there would have to be significant excess capacity in the system to be able to perform every procedure as soon as it is declared necessary, which would drive up costs and create an inevitable pressure to use that capacity by finding more cases or lowering the threshold for intervention. Hence, waiting lists may be regarded as a potentially helpful management tool for ensuring equitable access to appropriate health care services at a reasonable cost.

The majority of waiting list data to date have come from physician self reports. This may be problematic for several reasons. First, even physicians and surgeons performing the same procedure have different methods for referring patients to waiting lists and prioritizing them. A case regarded as urgent by one physician may be classified as elective by another. Second, physicians may use different methods of calculating waiting time. Third, in the absence of comprehensive computerized databases, estimates may be subject to recall bias. This is of particular concern because of the functional benefits that long waiting lists have for physicians. For example, long waiting lists may be used to leverage additional resources such as operating room time, potentially at the expense of other surgeons whose clinical needs may be more acute. Finally, waiting lists may also be used by the public as an indicator of the quality of service provided by a given physician. Therefore physicians with long waiting lists may actually be preferred in the belief that they provide better quality care. Because of these problems, confidence in the accuracy of waiting list data could be improved by routinely collecting data from sources other than individual clinicians .

A key consequence of health care reform has been to shift some of the responsibility for health service planning, resource allocation, and quality control from a provincial level to Regional

Health Authorities (RHAs), hospitals, and cancer organizations. Therefore, it would seem important that these organizations have access to valid waiting list data and use such data to ensure patients have equitable access to services, to monitor patients' outcomes, and to make appropriate re-allocations of resources. However, little is actually known about whether RHAs, hospitals, and cancer organizations have access to waiting list data or how they use them. The purpose of this component of the study was to begin to fill this gap. The specific objectives were to:

- ▶ determine what type of waiting list information is available to Canadian hospitals, cancer centres and RHAs;
- ▶ assess the quality and level of standardization of data available in these settings;
- ▶ determine how waiting list data are currently used by these organizations;
- ▶ assess organizational perceptions of the prevalence and seriousness of problems surrounding waiting lists; and,
- ▶ assess organizational opinions regarding potential solutions to waiting list problems.

2.0 Definitions

The term regional health authority (RHA) will be used throughout this chapter to describe organizations whose mandate includes the monitoring, planning, coordination and allocation of a variety of health care resources to service residents from a prescribed geographic location. The term RHA is meant to include district health boards, district health councils and similar organizations. Cancer agencies refer to organizations responsible for, among other things, cancer surveillance and the coordination of cancer diagnosis and/or treatment services. Cancer clinics refer to facilities whose primary mission is the diagnosis and treatment of cancer. The term cancer organization is used to refer to aggregated data from cancer clinics and cancer agencies.

3.0 Methods

3.1 Participants

Participants for the study included RHAs, public hospitals with more than 100 acute care beds (including pediatric treatment facilities), dedicated cancer clinics and treatment centres, as well as provincially based cancer agencies or boards. Long term care, psychiatric, and military hospitals were excluded from the study. The decision to exclude individual primary care providers such as physicians from the present study was based on the fact that a large national survey of physicians is conducted regularly by the Fraser Institute (Ramsay & Walker, 1995, 1997); see chapter 5 for a review of these and other physician surveys.

The names and other information for potential survey subjects were obtained from two sources: a computerized database of health care facilities produced by the Canadian Healthcare Association (1997) and a list of Canadian cancer centres and agencies supplied by the Saskatchewan Cancer Agency. The CHA database was updated to the end of March 1997 and includes, among other things, the name, address, CEO, hospital bed type and number of regional health authorities, health districts, health councils, and public hospitals in Canada. The list of cancer agencies and clinics was updated in 1997 and included the facility name, address, and the CEO's name.

3.2 Survey Design

Since it would have been too unrealistic to expect potential respondents to collect data on all types of waiting lists, the following parameters were used to select health care services for inclusion in the survey:

- ▶ a mix of acute, long term, and community based services;
- ▶ a mix of surgical, medical, and diagnostic procedures;
- ▶ services with relatively high volumes;
- ▶ services with a high probability of having a waiting list;
- ▶ services that have become a flashpoint for public discourse;
- ▶ services that could be described and would be performed in a relatively uniform manner across the country.

Based on these criteria, it was decided to question respondents about the following health care services: magnetic resonance imaging (MRI), coronary artery bypass graft surgery (CAB), hip or knee replacement, cataract removal, non-urgent outpatient psychiatric therapy, and radiation oncology. Initially, long term care was also included in this list. However, after consultation and pretesting, it became apparent that the diversity of terms, definitions and organization of services across the provinces and territories would make it extremely difficult to construct questions that would produce valid and reliable responses. We recognize that waits for some components of long term care services may be among the most problematic in the country and suggest that a follow-up project be dedicated to this increasingly important area of care.

It was also recognized that some definitions of waiting time include not only the period between a referral from a specialist to the performance of the service, but also the period it takes to receive a consultation with a physician or surgical specialist. Therefore, it was also decided to investigate waiting lists for receiving consultations with cardiac surgeons, orthopedic surgeons, ophthalmologic surgeons, psychiatrists, and oncologists.

A brief literature review was conducted for the purpose of identifying potential questions related to each of the study objectives. This yielded few suitable prototypes so the investigators generated a list of possible questions. Items were reviewed by a team of investigators at the Health Services Utilization Commission in Saskatchewan, as well as investigators at collaborating sites at the University of British Columbia and Queens University. After several iterations, a penultimate list of questions was pretested with a total of six senior administrators from hospitals and RHAs in British Columbia, Saskatchewan and Ontario. The final set of questions included on the surveys was selected to ensure:

- ▶ each of the study objectives was being addressed;
- ▶ respondents could complete the survey in a reasonable time;
- ▶ questions would be interpreted by respondents from different parts of the country, organizations and professional backgrounds in a consistent manner.

To facilitate the collection of background information and in recognition of their distinct mandates, it was necessary to develop slightly different versions of the survey for hospitals, cancer clinics, RHAs, and provincial cancer agencies. Moreover, since most of the selected services were unlikely to be provided by cancer agencies and clinics (e.g., CAB surgery), it was decided that questionnaires for cancer organizations would only ask about radiation oncology and consultations with radiation oncologists. Hence, four English and four French versions of the survey were produced. All versions of the survey maintained a common core of questions. English versions of the questionnaires are provided in Appendices 3.A to 3.D. English versions of the questionnaires were translated into French by Health Canada.

3.3 Procedure

Between February 12th and 16th, 1998, surveys and cover letters were mailed to the CEOs of 30 cancer agencies and clinics, 248 hospitals, and 171 regional health authorities. The letter outlined the purpose of the study, briefly described who was conducting it, and that the study had been endorsed by the Canadian Healthcare Association and the Canadian Nurses Association. It also emphasized the need for respondents to provide a corporate, rather than an individual view of waiting lists within their organization. As such, recipients were invited to direct the survey to those in their organization best able to respond. Recipients were given the option of returning the surveys by surface mail, fax, or filing a response on an internet site. Survey recipients were asked to forward their responses by March 6, 1998.

In an effort to maximize response rates, reminder notices were mailed to the CEOs of the target organizations between February 25th and 27th, 1998 (Appendix 3.E). In addition, the CEOs (or designates) from target organizations who had not returned the survey were telephoned between March 4 and March 30. The purposes of the telephone call were threefold. First, subjects were reminded to forward the questionnaire. Second, copies of the appropriate survey were faxed to those sites that had misplaced the original. Finally, using a prepared script, subjects were asked if they intended to respond, and if not, why not. Responses were coded into one of nine response categories (Appendix 3.F).

3.4 Analyses

Since the entire population of target organizations was sent a survey and respondents did not constitute a random sample, the data were analyzed using relatively simple descriptive techniques.

When analyzing results concerning the availability, quality, and use of local data (Part B of the questionnaire), methods varied according to whether responses were from a hospital, cancer organization or RHA. It was assumed that the responsibility of hospitals and cancer clinics is limited to those services provided through their institution. For example, it serves little purpose for a hospital to collect or manage CAB wait list data if they do not perform CAB surgery or have a cardiac surgeon. Therefore, results related to the collection, management, or use of in-house data were adjusted so that denominators included only hospitals and cancer clinics thought to offer the service. This was done by excluding organizations that consistently answered not applicable with respect to a given service type. In contrast, the responsibility of RHAs extends beyond those who receive a service within their district. RHAs are responsible for ensuring all their residents have access to essential health services. Therefore, unless otherwise noted, analyses regarding the collection, management and use of wait lists data included all RHAs that responded, not just those for which a given service was available within the region.

4.0 Results

4.1 Profile of Respondents

Of the 449 survey packages mailed, three hospital and four regional health authority packages were returned by the post office. Correct addresses were located and new packages sent to two of the four regional health authorities. Responses were received from eleven hospitals and four regions which had undergone restructuring and no longer fit the inclusion criteria (e.g., conversion to a long term care facility or health centre; elimination of the organization). Ten regional health authorities (District Health Councils) from Ontario had been merged with other Councils and were therefore dropped from the analysis. Hence, the total number of potential organizations in the study was 419, including 30 cancer centres/agencies, 234 hospitals and 155 regional health authorities.

Responses were received from 11 cancer clinics (44.0%), five (100%) cancer agencies, 77 hospitals (32.9%), and 63 regional health authorities (40.6%) for an overall response rate of 37.2 per cent. 47 An examination of response rates indicates that surveys were received from all provinces (Table 3.1). However, Quebec, Nova Scotia and Newfoundland had relatively low response rates. No surveys were received from Yukon, although three (27.3% of targeted organizations) were received from North West Territories. Overall, 33 per cent of the 156 responses were from Ontario, 19 per cent from Saskatchewan, and 10 per cent from Alberta. Only 11 per cent of responses were from Quebec. There was also a paucity of responses from the largest hospitals and regional health authorities in the country including those in Halifax, Montreal, Ottawa, London, Calgary and Vancouver. A list of respondents included in the analyses is provided in Appendix 3.G.

4.2 Profile of Non-respondents

The investigators successfully contacted 139 of the 262 organizations that did not return a survey, by telephone, to inquire about possible reasons for not returning questionnaires. Among those contacted 29 per cent indicated they intended to forward a completed questionnaire before the response deadline (although none were received)! Twenty eight per cent of non-respondents contacted indicated that they had forwarded their questionnaire to a colleague but were unaware of its present status. Eight per cent of non-respondents did not intend to complete the survey because they believed their response would be redundant with another organization in their region. This occurred most frequently when a health authority contained a single hospital or a cancer clinic resided within a hospital. Fifteen percent of non-respondents contacted refused to complete the survey on the grounds that they were too busy. Twenty per cent of the non-respondents contacted declined to complete the survey on the grounds that they did not keep waiting lists data and therefore felt the questionnaire was irrelevant to them. Small RHAs were most likely to fall into this category.

4.3 Who Has Wait List Data

Overall, 22 of the 63 regional health authorities (39.9%) that responded indicated they had access to a central waiting list registry for at least one type of scheduled service or consultation. Of the 22 with registries, 20 maintained the information themselves while 2

relied on some other group or agency to maintain the information. Among the 77 hospitals that responded, 47 (61.0%) maintained their own waiting lists for scheduled procedures or consultations. None of the hospitals relied on other agencies or organizations to keep waiting list data. Finally, 12 of the 16 cancer agencies/clinics (75.0%) indicated that they kept their own central waiting list or registry for scheduled services, while one indicated that some other group or agency maintained their information.

As shown in Table 3.2, the availability of waiting list data varies by the type of service and organization. In general, cancer organizations are most likely to have access to waiting list data. The availability of waiting list data in hospitals depends on service type. Over half of hospitals reported having some type of waiting list data for MRI, outpatient psychiatry and the three surgical services. Less than one third of hospitals had access to waiting lists for consultations with physician and surgical specialists. Waiting lists were least likely to be accessible to RHAs. When averaged across service type, less than 10 per cent of RHAs have access to wait list data. Waiting lists are least likely to be available to RHAs for highly specialized services (e.g., MRI, CAB, radiation oncology, consultation with a cardiac surgeon). However, less than 20 per cent of RHAs have access to even relatively common services such as hip/knee replacement, cataract surgery, and outpatient psychiatry.

Tables 3.3 to 3.5 provide details on what type of data is collected in hospitals, RHAs and cancer organizations. The interpretation of results from RHAs is difficult because so few of these organizations collect waiting list data. Among RHAs with data, the likelihood that they include basic information such as patient demographics, whether the service is urgent or elective, the name of the physician performing or ordering the service, or the patient's diagnosis varies by service type. A wide variety of data appears to be routinely collected for hip/knee replacement and cataract surgery, but not for outpatient psychiatry or consultations with physician specialists. Among hospitals and cancer organizations with access to waiting list data it is relatively common to routinely collect patient demographics, whether the service is urgent or elective, the name of the physician performing or ordering the service, and the patient's diagnosis. It is notable, however, that even straightforward information such as the level of urgency or diagnosis is not universally collected by any of the organization types.

4.4 Quality of Wait List Data

In order for a waiting list to be valid, the people assigned to it should have a legitimate need for the service in question. One method to address this is to ensure that referral or booking agents utilize some form of structured assessment procedure or clinical practice guideline. To address this issue participants were asked 'Are you using any structured evaluation method to assess the appropriateness of performing a procedure (e.g., use of clinical practice guideline, InterQual, etc.)?' The percentages of respondents who answered yes are shown in Table 3.6. Less than three per cent of RHAs have access to waiting list data that have been subjected to a structured assessment. While some of this is because few RHAs have access to wait list data, only 13 per cent of RHAs with wait list data (aggregated across service type) reported using a systematic means of assessing service appropriateness. About three quarters of cancer organizations use structured assessment methods for assigning patients to wait lists. The use of such methods among hospitals varies by service type, ranging from 60 percent of waiting lists for MRI to about 15 per cent of waiting lists for cataract surgery and various physician consultations.

One of the putative benefits of waiting lists is that they provide both patients and service providers with a buffer period to re-consider whether a given service is the best course of action. It is not uncommon for a condition to sufficiently abate to the point that the original service is no longer required. For example, one study of patients on a waiting list to receive a tonsillectomy found that 20 per cent of children and eight per cent of adults recovered sufficiently so as to negate the need for surgery (Freeland & Curley, 1987). Alternatively, the need for a service may be eliminated because of death or morbidity caused by an independent condition. Therefore, unless lists are routinely audited, they may contain significant numbers of patients that no longer require a service (for further discussion of these issues see chapter 5).

To assess auditing practices participants were asked, 'Do you routinely and systematically update/audit waiting lists in your hospital, region, clinic or agency?' Results, shown Table 3.7, indicate that the per cent of respondents answering yes was highly dependent on the organization and service type. The overwhelming majority of cancer organizations (>83%)

report auditing their waiting lists. Over 80 per cent of hospitals reported that they routinely audited wait lists for MRI, CAB and outpatient psychiatry. Other types of waiting lists in hospitals were audited, on average, by about two thirds of the respondents. Overall, relatively few RHAs reported using audited waiting lists. However, once again this is likely due to the fact that few RHAs have access to any kind of data, audited or otherwise. Over 90 per cent of RHAs with waiting list data for MRI, CAB, hip/knee replacement, and cataract surgery reported that they routinely audited them. Approximately two thirds of RHAs with other types of wait list data reported that they were routinely audited. When interpreting these results it is important to keep in mind that the terms routine and audit were not defined, and these were unvalidated self-reports. Respondents were free to apply their own interpretation. Therefore, the level of rigour and the frequency with which data are audited remains unknown.

While waiting may be advantageous or innocuous in some circumstances, in others it may produce negative consequences. Therefore, measures should be taken to ensure that patient outcomes are not irrevocably harmed by the time they must wait for a service. Participants were asked, Do you routinely collect or review information on the impact of waiting time on patient outcomes? Results shown in Table 3.8 suggest that the proportion of organizations that monitor patient outcomes varies by service and organization type. However, the monitoring of patient outcomes is far from routine. For example, patient outcomes associated with waiting for time-sensitive procedures such as CAB were only monitored by 43 per cent of the hospitals that performed this service. Less than 20 per cent of hospitals reviewed outcomes of patients waiting for hip/knee replacement, cataract surgery, and outpatient psychiatry. Fewer than 25 per cent of cancer organizations reported that they tracked the impact of waiting times on patient outcomes. Among RHAs, less than 5 per cent reported tracking patient outcomes associated with waiting for any of the procedures. One of the two RHAs with waiting list data for MRI reported that patient outcomes associated with waiting time were reviewed. Less than 5 per cent of RHAs with other types of waiting list data reviewed patient outcomes.

A variety of studies have reported wide variations in waiting lists and times between physicians, treatment centres, regions, and services (see chapter 5). At least part of the reason for these variances may be related to the way the concept of Awaiting time is defined. In order to make a valid comparison of waiting lists it is important to ensure that data are calculated using similar definitions and procedures (Cottrell, 1980). Table 3.9 shows that survey respondents with access to central registries use various methods for defining when a patient is entered on a waiting list. For example, among respondents that kept wait lists for CAB surgery, 23 per cent defined the start of the waiting period at the moment a patient was referred to a cardiac specialist; 54 per cent calculated it from the time a treatment decision was made and 15 per cent from the time a booking slip was sent to the surgical centre. Among respondents with waiting lists for hip or knee replacement, five per cent started the waiting period from the time of diagnosis or referral to an orthopedic surgeon, compared to 82 per cent who defined waiting time from the moment a booking slip was forwarded to the surgical centre.

Survey recipients were asked to use a four point scale (from excellent to poor) to rate the quality of wait list data in their region, hospital or clinic with respect to completeness (are data adequate to inform clinical decisions, for planning, monitoring and evaluation), standardization (are data consistent and comparable across departments and/or physicians) and timeliness (are data available when needed to inform clinical decisions and planning). Results are given in Table 3.10 and suggest that respondents regard data as fair to good on these dimensions.

One indicator of data quality is the perceived level of confidence that users place in the data. Participants were asked to use a four point scale to rate, how confident are you that your waiting list data accurately represent the need for the following services? As shown in Table 3.11, users' confidence is generally low with less than half indicating that they were confident or very confident. However, there is significant variation in confidence levels by service and organization type. Overall, hospital and cancer organizations have a higher degree of confidence in their data than RHAs. Confidence was also generally higher for the diagnostic or surgical interventions than for outpatient psychiatry or consultations with specialists.

Not only was respondents' confidence in their own data low, but they also rated the quality of waiting list data across Canada as quite poor. As shown in Table 3.12, no one believed that the quality of data was excellent. With the exception of cancer organizations, few respondents believed the data could even be classified as good. In fact, among organizations with an opinion, 31 per cent said that the quality of waiting list information in Canada was poor.

One potential reason for the lack of confidence in waiting list data may be the belief that service providers (e.g., physicians) consciously manipulate lists for the benefit of their patients or themselves. These so called gaming strategies might include inflating lists with low-need cases or overstating the urgency of a patient's condition. As shown in Table 3.13, respondents perceived that the incidence of at least occasional gaming was relatively low. Of the services listed, hip/knee replacement surgery (38 per cent), Radiation Oncology (37.5 per cent), consultation with radiation oncologists (33.3 per cent), and cataract surgery (29.9 per cent) were regarded as the most vulnerable to at least occasional gaming.

4.5 Uses of Wait List Data

Respondents with access to waiting list data were asked to indicate how they were used within their organization. Response categories included, prioritizing patients according to their need, reallocate resources within a department (e.g., between orthopedic surgeons), reallocate resources across departments, acquire new resources from outside the region/hospital/clinics' budget, other or don't know. Respondents were free to choose as many categories as applied to them. Results were reasonably consistent across organization types but differed by service type (Table 3.14). Respondents felt the data were most likely to be used to prioritize patients, although the nature and extent of the prioritization is unknown. The percentage of respondents indicating that they used wait list data to prioritize patients ranged from 95% for MRI to 57% for orthopedic consultations. The use of waiting list data to leverage new resources was highly dependent on the type of service. In general, waiting lists were most likely to be used to support requests for additional resources for MRI, CAB surgery, radiation oncology, and hip/knee surgery.

All respondents were asked to indicate what they believed to be the most important purpose of waiting lists. Results given in Table 3.15 indicate that all types of organizations believe the most important function of waiting lists is to monitor and ensure the fairest possible access to services for patients (45% of respondents). Prioritizing patients received the second highest number of endorsements (32% of respondents), while only 10 per cent of respondents believed the most important function of waiting lists was to assess the adequacy of service supply or capacity. Four percent saw their primary purpose as allocating resources among institutions or departments.

4.6 Perceived Seriousness of Waiting List Problems

One reason that RHAs, hospitals and cancer organizations may not keep or use waiting list data is that they do not perceive access to services as a problem. Table 3.16 provides information on the extent to which respondents perceive waiting lists are a problem in their jurisdiction. Results did not differ by organization type for the majority of services. However, results did differ according to the type of service. Overall, approximately 18 per cent of organizations didn't know if waiting lists were a problem. The services identified most often as usually or always a problem were MRI (50% of respondents), consultations with psychiatrists (43 %), CAB surgery (38 %) and hip/knee replacement (38%). In contrast, 88 per cent of participants answered that waiting lists for radiation oncology consultations were not a problem or only occasionally a problem.

Respondents with waiting list problems were asked to use a four point scale to rank how important a series of factors are for triggering action to solve their problems. Patient or public complaints (67%) and complaints from physicians or surgeons (61 %) were most likely to be regarded as important or very important for triggering action to solve these problems (Table 3.17). The only factor regarded as relatively unimportant by more than half of respondents was media reports. Interestingly 54 per cent rated waiting list data as important or very important.

It is useful to determine whether judgments about waiting list problems are subjective or objective in nature. While the availability of objective criteria does not preclude subjectivity,

objective judgments cannot be made without the use of explicit criteria. Ideally these criteria should be validated against outcomes of interest such as a change in a patient's condition or level of satisfaction. In an effort to determine whether judgments and actions were based on objective evidence, respondents were asked, Do you have specific criteria that signal when you should take action to reduce or lengthen waiting lists for the following [services]? The criteria listed included the number of patients, the length of the wait time for a service, changes in morbidity or mortality among persons on the wait list, and the use of established clinical guidelines or benchmarks. Respondents were free to check as many criteria as applied to them. All of the cancer organizations reported using some type of action criteria for radiation oncology (Table 3.18). With respect to consultations with radiation oncologists, eight percent either did not have action criteria, or did not know their status. The most common action criteria used in cancer organizations were related to patient volume or waiting time. Among hospitals offering a particular service, over 40 per cent had no criteria (Table 3.19). Among those with criteria, it was most common to use patient volume or waiting time. With the exception of CAB surgery, the use of clinical guidelines or health outcome data such as changes in patient morbidity was relatively rare (generally less than 20 per cent of respondents). The majority of RHAs did not know if they used action criteria or had no criteria (Table 3.20).

A key reason for recent concerns about waiting lists is the belief that waiting times for services have increased. Table 3.21 shows respondents perceptions of how waiting times have changed for various services over the past three years. The response format required them to choose whether they believed waiting time had increased or decreased. Approximately one third of respondents were unable to offer an opinion. The majority of respondents believed that waiting times had increased or greatly increased for every service included in the survey. Overall, MRI and surgical services waits were identified by the largest proportion of respondents as having increased or greatly increased over the previous three year period.

4.7 Perceived Solutions to Waiting List Problems

While respondents expressed concerns about waiting lists, they also felt at least moderately empowered to deal with at least some of these concerns. For example, when asked how much

control do you think your organization can exercise over the time people spend on waiting lists?, 69 per cent indicated that they had at least moderate control. The largest degree of control was perceived among cancer organizations and hospitals. Thirty seven per cent of all regional health authorities indicated that they had little or no control over the length of time people spend on waiting lists.

Organizations were asked to rate how important they believed a variety of factors were in determining how long people in their regions would have to wait for services. Results are shown in Table 3.22. Overall, 81 per cent of respondents believed inadequate resources to meet real needs is important or very important. Also likely to be rated as important or very important were the misallocation of resources such as operating room time to surgeons (52.9 %). The introduction of more effective (and safe) procedures (42%) was regarded as mildly important. Conversely, 75 per cent of respondents indicated that placing patients well in advance of when they really need service (i.e., placing patients on lists just in case they require the service), is not important at all or only somewhat important in determining waiting list length. Similarly, 73 per cent of respondents believe that requiring patients to wait because it may benefit their condition is relatively unimportant. Other factors rated as being relatively unimportant in determining patient waiting times were the existence of incentives to increase waiting times, patient preferences to defer service, and patient being unaware that they may be able to receive faster service from alternative physicians or surgeons.

Finally, respondents were asked, Where you believe a genuine access problem exists, how effective would each of the following be in reducing waiting list lengths and times? Responses were transformed into a five point scale (2 = very effective; 0 = no effect; -2 = very detrimental). Results shown in Table 3.23 suggest that hospital and regional health authorities believe the most effective strategies for improving access problems include standardizing assessment procedures to determine service needs, increasing the supply of operating room time or equipment, changing the method for funding programs, and developing practice guidelines for monitoring patients. Cancer organizations believed that increasing the supply of equipment (e.g., for MRIs and/or radiation therapy) would be the greatest benefit. All organization types felt that reducing the supply of physicians or surgeons would have a

detrimental effect on waiting lists and that factors such as increasing the supply of hospital beds or changing the physician payment system would have only a marginal positive benefit.

5.0 Discussion

5.1 Summary and Integration of Results

Overall results suggest that, despite increased responsibilities for resource allocation and surveillance of health service quality:

- ▶ only a minority of RHAs and hospitals have access to waiting list data;
- ▶ the type and quality of available data is highly variable, especially for hospitals and RHAs;
- ▶ few standardized criteria are being used to define basic concepts (e.g., waiting time) or to screen or prioritize patients;
- ▶ few standardized methods are in place to monitor patient outcomes or designate when actions are required to increase or decrease waiting lists;

On a more positive note, despite the perception that waiting list problems are on the rise, respondents believe they have at least a moderate degree of control over them. Many organizations recognized the positive potential of initiatives such as standardizing assessment procedures and the use of practice guidelines. However, most also believe that waiting lists are highly influenced by resource supply, despite the fact that the research literature offers little evidence that adding resources necessarily reduces waiting list problems (see Chapter 5).

5.2 Limitations and Caveats

When interpreting the results of this study, several considerations must be kept in mind. First, the overall response rate was low, even for a self-report, mail-based survey. The response rate was particularly low for hospitals and organizations east of Ontario. Responses were heavily weighted by hospitals and RHAs from Ontario, Saskatchewan and Alberta. Perhaps most problematic of all was the paucity of responses from large urban RHAs and hospitals. For example, no responses were received from Victoria, Vancouver, Ottawa, London, Quebec

City, or Halifax, while only one hospital in each of Calgary and Montreal returned a survey. On the other hand, seven hospitals from Metropolitan Toronto, four hospitals from Winnipeg, as well as RHAs from Metro Toronto, Edmonton, and the Fraser Valley responded. The under-representation of large urban organizations is a concern since they perform many of the most specialized procedures in the country. Their regional status also means they provide a large share of health care services. As such, large urban centres may be more vulnerable to chronic waiting list problems. We can only speculate why the largest (and presumably some of the most sophisticated) organizations chose not to respond. It is plausible that they were concerned that their lack of data may have become a politically sensitive issue. Conversely, the availability of valid and reliable data in these organizations may have reduced concerns about the topic. Hence, in the face of competing demands, completing a survey on wait lists may not have been a priority. However, based on the results of the follow-up telephone survey to non-respondents, the most likely explanation is that the questionnaire was more likely to be misplaced within large organizations.

The low and potentially biased nature of the responses means that it was not appropriate to perform a series of sub-analysis based on factors such as the relative size of an organization, geography, etc.. Moreover, the estimates can be unstable and therefore misleading. For example, depending on how the data are analyzed, either a very high or a very low proportion of RHAs effectively manage waiting lists for services such as MRI and CAB surgery. When the analysis is limited to RHAs that collect this type of information, it appears that the majority collect a wide variety of information (e.g., patient demographics, patient priority, diagnosis, etc.) and perform tasks such as routine auditing, structured assessments, and so on. However, close inspection of the data reveals that these estimates are based on only one or two respondents. On the other hand, including all RHAs (n=63) in the analysis makes it appear that few of these organizations audit their data or use structured assessment methods. However, once again, close inspection shows that the need for these tasks is diminished because so little data are available.

The low response rate made it necessary to aggregate some of the responses across organization types. However, this may have reduced the precision of estimates with individual

organization types. Moreover, it also creates the possibility that responses from some areas of the country are double-counted. This could occur, for example, where responses were received by a RHA, hospital, and/or cancer clinic within the same region.

Another limitation of the results is related to the self report format. No attempt could be made in the time-frame of this study to validate the answers provided. Like physician self-reports, this is problematic because of recall bias and the functional benefits associated with having long waiting lists (e.g., a tool to leverage additional resources). Although respondents were explicitly asked to provide a corporate view, it is also possible that opinion-related questions reflected the perspective of only a handful of people rather than providing an organization-wide perspective. Another problem with the self-report format is that respondents must interpret terms on their own. Hence, there may have been variation in the way words and concepts such as prioritization, auditing, and timeliness were interpreted.

5.3 Waiting Lists: Bomb, Boon, or Bust?

What, then, do these results tell us about the waiting list situation in Canada? Are waiting lists a kind of bomb that is about to destroy one of the principal tenets of the health care system (equitable access to quality care), or are they a boon to hospitals, cancer organizations, and regional health authorities for ensuring equity, effectiveness and cost effectiveness? Results of the present study suggest that neither claim can be validated at the present time. It is clear that in their present form waiting lists should not be regarded as a valid indicator of health care system access problems because the lists themselves are not valid, reliable, or comprehensive. It is not possible to determine if the true burden of illness associated with queuing has increased, decreased, or stayed the same over the last few years.

It is likely that the full potential that waiting lists have for improving the equity, effectiveness and efficiency of services is not being realized. Waiting lists cannot be used to improve the allocation of resources until the data are collected in a standardized and comprehensive manner. In their present form it would be unwise to compare waiting lists within or between institutions. Failure to use standardized assessment tools or properly audit waiting lists increases the likelihood that patients will receive unnecessary or inappropriate treatment or

will remain or be placed on lists when they need not be. Moreover, few attempts have been made to prioritize patients based on need or potential for improvement. The lack of action to prioritize patients using something other than relatively crude designations such as emergent, urgent or elective increases the risk that persons with relatively insignificant conditions will receive treatment ahead of those whose conditions have a profound impact on the length or quality of their life. Finally, there are few mechanisms to systematically monitor the impact of waiting time on patient outcomes or to decide when action is required. As a consequence, it is not possible to state with any confidence whether waiting times are causing avoidable harm.

In summary, when properly organized, managed and calibrated, waiting lists can be an important planning tool for monitoring whether patients have equitable access to quality health care. However, there is insufficient evidence at the present time to suggest that the waiting list data currently available to RHAs, hospitals, and to a lesser extent cancer organizations, are a valid and reliable indicator of access to quality health care.

Table 3.1:

Responses by Province and Organizational Type

	Hospitals			Regions			Cancer			All		
	Total #	# Responses	Response Rate	Total #	# Responses	Response Rate	Total #	#	Response Rate	Total #	#	Response Rate
NF	1	0	0.0%	14	3	21.4%	1	1	100.0%	16	4	25.0%
PE	1	0	0.0%	5	2	40.0%	1	0	0.0%	7	2	28.6%
NS	8	2	25.0%	5	0	0.0%	1	1	100.0%	14	3	21.4%
NB	8	2	25.0%	8	5	62.5%	2	2	100.0%	18	9	50.0%
QC	79	13	16.5%	18	4	22.2%	0	0	0.0%	97	17	17.5%
ON	81	38	46.9%	24	11	45.8%	11	3	27.3%	116	52	44.8%
MB	11	5	45.5%	10	2	20.0%	1	1	100.0%	22	8	36.4%
SK	6	3	50.0%	32	24	75.0%	3	2	66.7%	41	29	70.7%
AB	12	5	41.7%	18	7	38.9%	7	4	57.1%	37	16	43.2%
BC	27	9	33.3%	10	2	20.0%	3	2	66.7%	40	13	32.5%
NWT	0	0	0.0%	11	3	27.3%	0	0	0.0%	11	3	27.3%
YT	0	0	0.0%	0	0	0.0%	0	0	0.0%	0	0	0.0%
Total	234	77	32.9	155	63	40.6	30	16	53.3%	419	156	37.2

Table 3.2:

**Per Cent of Organizations that
Collect Waiting List Data for
Various Services**

	Hospitals n=77	Regions n=63	Cancer n=16
MRI	56	3	
CAB	55	2	
Hip/Knee	61	16	
Cataract	59	21	
Psychiatric Outpatient	63	16	
Consultation with Cardiac Surg	10	3	
Consultation with Psychiatrist	38	17	
Consultation with Ophthalmologist	30	13	
Consultation with Orthopedic Surgeon	25	14	
Radiation Oncology		3	81
Consultation with Rad. Oncol.		0	81

Table 3.3:

Per cent of RHAs with Access to Data that
Collect Various Types of Information

	Patient Demographics				
	Patient	Urgency	Physician	Diagnosis	Other
MRI (<i>n</i>=2)	100	100	100	100	0
CAB (<i>n</i> = 1)	100	100	100	100	0
Hip/knee (<i>n</i> = 10)	90	90	100	90	30
Cataract (<i>n</i> = 13)	85	85	92	85	15
Outpatient Psychiatry (<i>n</i> = 10)	60	60	40	30	0
Consult with Cardiac Surg. (<i>n</i>=2)	50	50	50	50	0
Consult with Psychiatrist (<i>n</i>=11)	64	55	45	27	0
Consult with Ophthalmologist (<i>n</i>=8)	50	63	50	38	0
Consult with Orthopedic Surg (<i>n</i> = 9)	56	56	56	56	0

Table 3.4:

**Per cent of Hospitals Offering a Service
And With Access to Data That Collect
Various Types of Information**

	Patient Demographics	Urgency	Physician	Diagnosis	Other
MRI (<i>n</i>=15)	93	93	80	100	40
CAB (<i>n</i>=11)	64	82	55	55	27
Hip/knee (<i>n</i>=33)	91	88	100	91	21
Cataract (<i>n</i>=32)	91	81	94	91	19
Psychiatric Outpatient (<i>n</i>=29)	83	45	76	79	17
Consult with Cardiac Surg. (<i>n</i>=8)	75	88	63	75	25
Consult with Psychiatrist (<i>n</i>=29)	79	59	72	79	17
Consult with Ophthalmologist (<i>n</i>=23)	74	70	78	74	13
Consult with Orthopedic Surg. (<i>n</i>=19)	79	68	84	68	11

Table 3.5:

**Per cent of Cancer Organizations with Access
to Data and Who Offer a Service that
Collect Various Information**

	Patient	Urgency	Physician	Diagnosis	Other
Demographics					
Radiation Oncology (<i>n</i> = 13)	92	77	77	92	54
Consult with Rad. Oncol (<i>n</i> =13)	92	75	85	85	54

Table 3.6:

**Per cent of Organizations Using Structured
Methods to Assess the Appropriateness
Of Patients on Wait Lists**

	Hospital	Region	Cancer
MRI	60	2	
CAB	50	2	
Hip/knee	30	3	
Cataract	15	2	
Outpatient Psychiatry	32	2	
Consult with Cardiac Surg.	38	0	
Consult with Psychiatrist	15	2	
Consult with Ophthalmologist	16	0	
Consult with Orthopedic Surg.	13	2	
Radiation Oncology		3	75
Consultation with Rad. Oncol.		0	73

Table 3.7:

**Per cent of Organizations That Routinely
Audit Their Waiting**

	Hospital	Region	Cancer
MRI	80	3	
CAB	88	3	
Hip/Knee	67	17	
Cataract	69	16	
Outpatient Psychiatry	81	8	
Consultation with Cardiac Surg.	67	2	
Consultation with Psychiatrist	75	10	
Consultation with Ophthalmologist	58	6	
Consultation with Orthopedic Surg.	41	8	
Radiation Oncology			100
Consult with Rad. Oncol.			83

Table 3.8:
Per cent of Organizations that Routinely
Review Information on the Impact of
Waiting Lists on Patient Outcomes

	Hospitals		Regions		Cancer	
	%	N	%	N	%	N
MRI	35	17	2	63		
CAB	43	7	2	63		
Hip/knee	17	30	5	63		
Cataract	19	32	5	63		
Outpatient Psychiatry	18	22	2	63		
Consultation with Cardiac Surg.	33	6	0	63		
Consultation with Psychiatrist	10	20	2	63		
Consultation with Ophthalmologist	20	20	0	63		
Consultation with Orthopedic Surg.	13	16	2	63		
Radiation Oncology	-	-	0	63	17	12
Consultation with Rad. Oncol.	-	-	0	63	25	12

Table 3.9:

**Per cent of Organizations With Waiting List Data Using
Various Definitions For Entering a Patient on a Waiting List**

	Referral to Specialists	At Treatment Decision	Clinic Notified	Other	Don't Know
MRI	5	16	58	16	5
CAB	23	54	15	8	0
Hip/Knee	5	14	82	0	0
Cataract	4	20	76	0	0
Outpatient Psychiatry	29	11	42	8	11
Radiation Oncology	39	44	11	6	0

Table 3.10:

**Mean Ratings of Local Waiting List Data Quality with
Respect to Completeness, Standardization and Timeliness**

(4=Excellent; 1= Poor)

	Completeness			Standardization			Timeliness		
	Mean	SD	N	Mean	SD	N	Mean	SD	N
MRI	2.6	1.1	27	2.4	1.2	24	2.4	1.1	25
CAB	2.7	1.1	17	2.8	1.1	16	2.5	1.1	17
Hip/Knee	2.7	0.9	55	2.7	1.1	51	2.8	1.0	52
Cataract	2.5	1.0	52	2.6	1.0	50	2.4	1.0	49
Outpatient Psychiatry	2.2	1.0	46	2.3	0.9	38	2.6	0.9	45
Consultation with Cardiac Surg.	2.3	1.1	16	2.1	1.0	16	2.3	1.1	16
Consultation with Psychiatrist	2.3	0.9	42	2.2	0.8	36	2.2	0.9	42
Consultation with Ophthalmologist	2.5	1.0	34	2.4	1.0	33	2.3	1.0	33
Consultation with Orthopedic Surg.	2.3	1.0	35	2.3	1.0	31	2.2	1.0	33
Radiation Oncology	2.6	1.1	24	2.5	1.1	22	2.3	1.1	21
Consultation with Rad. Oncol.	2.6	1.0	13	2.5	0.9	11	0.0	0.0	0

Table 3.11:

Per cent of Organizations that are Confident or Very Confident
with Local Waiting List Accuracy

	Hospitals		Regions		Cancer		All	
	%	N	%	N	%	N	%	N
MRI	58.3	24	6.7	15			34.9	43
CAB	61.5	13	12.5	16			34.5	29
Hip/Knee	53.3	45	40.0	30			48.0	75
Cataract	63.6	44	48.4	31			57.3	75
Outpatient Psychiatry	44.7	38	25.0	28			36.4	66
Consultation with Cardiac Surg.	37.5	16	11.8	17			24.2	33
Consultation with Psychiatrist	54.5	33	16.0	25			37.9	58
Consultation with Ophthalmologist	39.4	33	20.0	25			31.0	58
Consultation with Orthopedic Surg.	31.6	38	25.9	27			29.2	65
Radiation Oncology			18.8	16	71.4	14	43.3	30
Consultation with Rad. Oncol.			0	0	73.3	15	73.3	15

Table 3.12: **Perceived Quality of Wait List Information in Canada**

	Excellent	Good		Fair		Poor		Don't know	
		%	N	%	N	%	N	%	N
Hospitals	-	11.8	8	35.3	24	30.9	21	22.1	15
Regions	-	7.4	4	27.8	15	31.5	17	33.3	18
Cancer Org.	-	35.7	5	21.4	3	28.6	4	14.3	2
All	-	12.5	17	30.9	42	30.9	42	25.7	35

Table 3.13:

Percent of Organizations that Believe Local Waiting Lists are at Least Occasionally Subject to Gaming

	Hospitals		Regions		Cancer		All	
	%	N	%	N	%	N	%	N
MRI	32.0	25	21.1	19			27.3	44
CAB	23.1	13	15.8	19			18.8	32
Hip/Knee	39.6	48	35.5	31			38.0	79
Cataract	28.9	45	31.3	32			29.9	77
Outpatient Psychiatry	17.9	39	18.5	27			18.2	66
Consultation with Cardiac Surg.	16.7	18	15.0	20			15.8	38
Consultation with Psychiatrist	22.5	40	14.8	27			23.0	61
Consultation with Ophthalmologist	23.5	34	22.2	27			21.3	61
Consultation with Orthopedic Surg.	20.6	34	22.2	27			19.4	67
Radiation Oncology			10.0	20	50.0	14	37.5	24
Consultation with Rad. Oncol.			0.0	0.0	33.3	5	33.3	15

Table 3.14:

**Percent of Respondents with Waiting List
Data Who Use Them for Specified Purposes**

	Prioritize	Reallocate	Reallocate	Acquire New	Other	Don't know
MRI (n=19)	95	37	21	47	0	0
CAB (n=12)	67	25	17	59	17	8
Hip/Knee (n=44)	80	30	20	30	5	2
Cataract (n=44)	80	18	16	16	0	5
Outpatient Psychiatry (n=35)	80	20	11	11	0	9
Consultation with Cardiac Surg. (n=8)	75	13	0	13	0	13
Consultation with Psychiatrist (n=33)	82	6	6	12	3	12
Consultation with Ophthalmologist (n=25)	72	8	8	8	0	12
Consultation with Orthopedic Surg. (n=23)	57	4	4	13	4	13
Radiation Oncology (n=20)	75	40	30	25	5	5
Consultation with Rad. Oncol (n=13)	69	69	38	46	8	0

Table 3.15:

Organization's Opinions About the Most Important

Purpose of Waiting Lists

(% endorsing item)

	Hospitals		Regions		Cancer		All	
	%	N	%	N	%	N	%	N
Monitor patient access	47.0	31	40.4	21	58.3	7	45.4	59
Prioritize patients	30.3	20	38.5	20	16.7	2	32.3	42
Assess service capacity	9.1	6	7.7	4	25.0	3	10	13
Allocate resources to institutions	4.5	3	0.0	0	0	0	3.8	5
Other	4.5	3	0.0	0	0	0	2.3	3
Don't Know	3.0	2	9.6	5	0	0	5.4	7
Allocate resources to physicians	1.5	1	3.8	2	0	0	0.8	1

Table 3.18:

**Per Cent of Cancer Organizations That Use Various
Criteria to Take Action to Alter Waiting Lists**

	No Criteria	Number of Patients	Waiting Time	Change in Morb./Mort.	CPG or Benchmark	Other	Don't Know
Radiation Oncology Consultation with Rad. Oncol.	0	34	38	3	25	0	0
	4	32	36	4	21	0	4

Table 3.19:

**Per Cent of Hospitals Offering a Service That Use
Various Criteria to Take Action to Alter Waiting Lists**

	No Criteria	Number of Patients	Waiting Time	Change in Morb/Mort	CPG or Benchmark	Other	Don't Know
MRI (<i>n</i>=19)	42%	37%	47%	11%	16%	16%	0%
CAB (<i>n</i>=13)	54%	38%	38%	38%	23%	8%	0%
Hip/Knee (<i>n</i>=45)	49%	29%	36%	16%	9%	7%	7%
Cataract (<i>n</i>=46)	48%	37%	35%	13%	4%	7%	7%
Outpatient Psychiatry (<i>n</i>=39)	46%	38%	28%	13%	8%	3%	8%
Consultation with Cardiac Surg. (<i>n</i>=17)	41%	18%	35%	18%	0%	0%	18%
Consultation with Ophthalmologist (<i>n</i>=33)	55%	21%	15%	6%	3%	3%	15%
Consultation with Orthopedic Surg. (<i>n</i>=35)	51%	14%	9%	11%	3%	3%	17%
Consultation with Psychiatrist (<i>n</i>=42)	38%	40%	29%	7%	12%	5%	7%

Note: Respondents could select more than one category

Table 3.20:

Per cent of Regions That Use Various Criteria
to Take Action to Alter Waiting Lists

	No Criteria	Number of	Waiting	Change in	CPG or	Other	Don't
MRI	23%	0%	5%	0%	2%	0	77%
CAB	18%	2%	7%	2%	2%	0%	75%
Hip/Knee	22%	15%	24%	0%	2%	0%	52%
Cataract	33%	11%	17%	0%	2%	0%	48%
Outpatient Psychiatry	30%	13%	9%	2%	7%	2%	52%
Consultation with Cardiac Surg.	22%	0%	4%	0%	2%	0%	71%
Consultation with Ophthalmologist	35%	9%	7%	2%	0%	0%	58%
Consultation with Orthopedic Surg.	33%	13%	4%	0%	0%	0%	59%
Consultation with Psychiatrist	37%	9%	4%	2%	2%	0%	57%
Radiation Oncology	22%	0%	2%	2%	2%	0%	70%

Notes:

Table 3.21:

Respondent's Perceived Changes in Waiting Time Over the Past

	Greatly %	Increased %	Decreased %	Greatly %	Don't Know %
MRI (<i>n</i> =53)	17.0	37.7	9.4	3.8	32.1
CAB (<i>n</i> =46)	10.9	34.8	13.0	0	41.3
Hip/Knee (<i>n</i> =88)	10.2	46.6	18.2	1.1	23.9
Cataract (<i>n</i> =74)	14.1	31.8	21.2	5.9	27.1
Outpatient Psychiatry (<i>n</i> =72)	5.6	48.6	18.1	1.4	26.4
Consultation with Cardiac Surg. (<i>n</i> =51)	3.9	37.3	9.8	0	49
Consultation with Psychiatrist (<i>n</i> =69)	2.9	40.6	11.6	1.4	43.5
Consultation with Ophthalmologist (<i>n</i> =78)	7.9	34.2	21.1	0	36.8
Consultation with Orthopedic Surg. (<i>n</i> =80)	15	38.8	15.0	2.5	28.8
Radiation Oncology (<i>n</i> =58)	1.7	37.9	29.3	0	31.0
Consultation with Rad. Oncol. (<i>n</i> =16)	6.3	43.8	31.3	6.3	12.5

Table 3.22:

**Per Cent of Organizations that Perceive Specified Factors
Determine How Long People Are on Waiting Lists**

	Not at all important	Somewhat important	Important	Very important	Don't know
	%	%	%	%	%
N=123 (except for "other" where n=16)					
Inadequate resources	6.3	7.1	21.4	59.5	5.6
Misallocation of resources	19.5	16.3	23.6	29.3	11.4
There are incentives to increase waiting lists	64.5	7.4	5.8	1.7	20.7
Procedures are becoming more effective/safe	17.8	20.3	32.2	10.2	19.5
Patients more inclined to undergo treatment	33.9	28.1	18.2	2.5	17.4
Patient preference to defer	30.3	34.4	11.5	4.9	18.9
Patients placed on lists "just in case"	53.7	21.1	8.9	1.6	14.6
Patients unaware of alternatives	44.6	19.0	12.4	8.3	15.7
Mismanagement of waiting lists	40.2	19.7	15.4	6.8	17.9
Waiting may be beneficial to patient's condition	52.5	20.3	5.1	1.7	20.3
Other	18.8	12.5	0.0	37.5	31.3

Table 3.23:

Perceived Effectiveness of Specified Strategies

(2=very effective; 0=no effect; -2=very detrimental)

	Hospital		Regions		Cancer	
	Mean	N	Mean	N	Mean	N
Standardize assessment procedures	1.2	49	1.3	43	0.8	11
Increase supply of Operating Room time	1.3	53	1.1	39	0.3	10
Increase supply of equipment (e.g., MRI, Radiation)	1.1	49	0.9	41	1.3	12
Change the method of funding programs	1.1	43	0.9	34	1.1	10
Develop guidelines for monitoring service	1.0	55	0.9	40	0.6	10
Change physician attitudes	0.8	51	1.1	37	0.2	11
Improve methods for structuring waiting lists	0.8	54	0.9	39	0.2	11
Change public attitudes	0.8	48	0.9	41	0.3	13
Improve methods for maintaining waiting lists	0.7	54	0.8	38	0.5	11
Increase supply of physicians/surgeons	0.7	60	0.8	44	0.8	12
Pool waiting lists across regions	0.5	42	0.7	36	0.0	13
Pool waiting lists across facilities	0.6	44	0.8	36	0.1	13
Change physician payment system	0.6	41	0.6	34	0.2	11
Increase supply of hospital beds	0.5	57	0.4	41	0.2	11
Reduce the number of physicians/surgeons	-1.1	49	-0.8	39	-1.1	12

APPENDIX 3.A

Cover Letter and Questionnaire Sent to Regional Health Authorities, Districts and Counsels



HEALTH SERVICES UTILIZATION AND RESEARCH COMMISSION

Box 46 103 Hospital Drive C Saskatoon, Saskatchewan S7N 0W8
Telephone: (306) 655-1500 C Fax: (306) 655-1462

February 5, 1998

Dear:

We are writing to request your help to examine health service waiting lists in Canada. The current absence of dispassionate and comprehensive information about the state of waiting lists is a substantial impediment to an accurate portrayal of our health care system. In association with Drs. Morris Barer and Sam Sheps of the University of British Columbia and Dr. Sam Shortt of Queen's University, the Health Services Utilization and Research Commission of Saskatchewan (HSURC) is undertaking a national survey of hospitals, regional health authorities, and cancer centres to collect objective data on the nature and quality of health service waiting lists.

HSURC is an arms-length, provincially funded government agency with a mandate to assess the health system and recommend evidence-based changes. The research project is being funded by Health Canada and has been endorsed by the Canadian Health Care Association and the Canadian Nursing Association.

The enclosed questionnaire is part of a broader initiative aimed at increasing our understanding of waiting list circumstances and uses. Other project activities include a review of the literature, a survey of professional and consumer associations, as well as interviews with key officials in provincial and territorial Ministries of Health. HSURC is responsible for collecting and analyzing the enclosed survey. Since it is not feasible to collect data on all types of health services, we are limiting our inquiry to a representative group of diagnostic and treatment services. Anonymous, aggregated survey results will be used by the three research teams to prepare a report to Health Canada and for publication in scholarly journals.

Your assistance in completing the questionnaire will help ensure our results are as comprehensive and accurate as possible. We are interested in obtaining your organization's corporate view, and would ask that the survey be directed to and completed by those who can respond on your collective behalf. Please note that the term regional health authority is meant to include regional health districts and district health councils.

In order to provide a preliminary report to Health Canada by the end of their fiscal year, we request that you forward your response **before March 6, 1998**. The survey may be completed and sent over the Internet in either English or French **by logging on to our project website at <http://www.sdh.sk.ca/regionalwlq>**. If you choose to complete the survey over the Internet, you **must** enter your **Survey Number** located at the top right hand corner of the first page of the paper questionnaire. Alternatively, hard copies of the survey may be faxed (306-655-1462) or mailed to the Principal Investigator for the Saskatchewan site, Paul McDonald, at Box 46 - 103 Hospital Drive, Saskatoon, SK. S7N 0W8. If you received both English and French versions of the questionnaire and you have elected to submit your response by fax or mail, please forward only one copy in the language of your choice. For the convenience of those who have not returned their questionnaire, we will provide a telephone reminder near the due date.

Study results will be posted on the HSURC Website (<http://www.sdh.sk.ca/hsurc/>) after April 17, 1998. If you have any questions or concerns about the enclosed survey, or our project in general, please contact Dr. Paul McDonald at 1-800-655-1599 or mcdonaldp@sdh.sk.ca.

Sincerely,

A. Stewart McMillan, MB, ChB, CCFP, FCFP
Chair

Steven Lewis
CEO and Project Co-investigator

Please respond with your most recent data, preferably 1997

RESPONSES REQUIRED BY MARCH 6, 1998.

SURVEY NUMBER

Section A. GENERAL REGIONAL/DISTRICT INFORMATION

- A1. Your health region/district is _____
in the province/territory of: _____
- A2. What is the population of your region/district, to the nearest 1000? _____
- A3. Which of the following services are provided within your region/district? (check all that apply):
- ☐ Any hospital services
 - ☐ Secondary hospital services
 - ☐ Tertiary hospital services
 - ☐ Quaternary hospital services
 - ☐ Radiation oncology
- A4. Check the statement below that best describes your region/district: (check only one item)
- ☐ Overall, most of the services our region/district provides are for residents from **within** our health region/ district.
 - ☐ Overall, most of the services our region/district provides are for residents from **outside** our health region/ district.
 - ☐ Overall, our region/district provides about the same amount of services to residents from inside our health region/ district as for outside residents.
- A5. The population in our region/district uses approximately:
- _____ acute care patient-days per 1000 population per year (excluding psychiatry and rehabilitation)
 - _____ physician visits per 1000 population per year
 - _____ acute psychiatric care beds per 1000 population per year

Section B. WAITING LIST CIRCUMSTANCES

Central waiting list registries in the section below refers to a compilation of waiting list information that is mandated and maintained by a region/district and housed in a central place designated by the region/district.

- B1. Does your region/district maintain a central waiting list for scheduled procedures or consultations (e.g., Magnetic Resonance Imaging, elective surgery, outpatient psychiatry, radiation oncology, consultations with physician specialists)?

☐ Yes (go to next question, B2.)

☐ No

→ If no, do some other groups or agencies maintain waiting list registries that you routinely use or have access to?

☐ Yes (go to next question, B2.)

☐ No



If no, skip through to Section C

B2. If a central waiting list registry is maintained, what role does the region perform? (check all that apply)

- ☐ Monitor waiting list data compiled and provided by others, (e.g., hospitals)
- ☐ Actively collect and update waiting list data
- ☐ Use waiting list data to manage resources
- ☐ Analyze data
- ☐ Coordinate between lists/services
- ☐ Other (please specify) _____

B3. What type of information is collected by the central waiting list registry for the following procedures? (put a check mark in all the cells that apply)

PROCEDURE	TYPE OF INFORMATION						
	Patient Demographics	Categories to designate Urgent/ Elective	Physician /Surgeon who performs the procedure or who patient visits	Diagnosis	Other	Don't Know	Not Applicable
Magnetic Resonance Imaging							
Coronary artery bypass graft surgery							
Hip/knee surgery							
Cataract surgery							
Non-urgent out-patient psychiatric treatment							
Radiation oncology							
Consultation with Cardiac surgeon							
Consultation with Psychiatrist							
Consultation with Ophthalmologic Surgeon							
Consultation with Orthopedic Surgeon							

B4. For each category below, indicate when a person is considered to have been entered on a waiting list:
(1=When referred to surgeon/specialist for examination, 2=When decision for surgery/treatment has been made, 3=When hospital is notified with a booking request, 4=Other (please specify), 5=Don't know, 6=Not applicable)

- ☐ Magnetic Resonance Imaging
- ☐ Coronary artery bypass graft surgery
- ☐ Hip/knee surgery
- ☐ Cataract surgery
- ☐ Radiation Oncology
- ☐ Non-urgent out-patient psychiatry treatment

B5. Please provide information on your region/district waiting lists for each of the following procedures during 1997: (*Waiting time is the interval of time between the notification to book a surgery or service until the date the procedure or service has been performed*)

	Average time (weeks) on waiting list	Median time (weeks) on waiting list	Average number of people on waiting list (per week)	Don't know	Not applic- able
Magnetic Resonance Imaging					
Coronary artery bypass graft surgery					
Hip/knee surgery					
Cataract surgery					
Non-urgent out- patient psychiatric treatment					
Radiation Oncology					
Consultation with Cardiac surgeon					
Consultation with Psychiatrist					
Consultation with Ophthalmologic Surgeon					
Consultation with Orthopedic Surgeon					

- B6.** Within your region/district, who is **primarily** responsible for making decisions about resources, and prioritizing patients based on waiting list data for the following procedures? (1=Individual physicians/surgeons, 2=Individual departments, 3=Facility administrators, 4=Regional/district administrators, 5=Provincial Ministry/Department of Health, 6=Other, 7=Don't know, 8=Not applicable)

PROCEDURE	Resource Allocation	Prioritizing Patients
Magnetic Resonance Imaging		
Coronary artery bypass graft surgery		
Hip/knee surgery		
Cataract surgery		
Non-urgent out-patient psychiatric treatment		
Radiation oncology		
Consultation with Cardiac surgeon		
Consultation with Psychiatrist		
Consultation with Ophthalmologic Surgeon		

- B7.** Please indicate how waiting list data are used in your region/district for each of the following procedures: (please put a check mark in all the cells that apply)

PROCEDURE	PURPOSE						
	Prioritize patients according to their need	Reallocate resources within a department (e.g., between Orthopedic surgeons)	Reallocate resources across departments	Acquire new resources from outside the region's budget	Other	Don't know	Not applicable
Magnetic Resonance Imaging							
Coronary artery bypass graft surgery							
Hip/knee surgery							
Cataract surgery							
Non-urgent out-patient psychiatric treatment							
Radiation oncology							
Consultation with Cardiac surgeon							
Consultation with Psychiatrist							
Consultation with Ophthalmologic Surgeon							
Consultation with Orthopedic Surgeon							

B8. Are you using any structured evaluation method to assess the appropriateness of performing a procedure (e.g., use of clinical practice guidelines, InterQual, etc.)?

PROCEDURE	Yes	No	Don't Know	Not Applicable
Magnetic Resonance Imaging				
Coronary artery bypass graft surgery				
Hip/knee surgery				
Cataract surgery				
Non-urgent out-patient psychiatric treatment				
Radiation oncology				
Consultation with Cardiac surgeon				
Consultation with Psychiatrist				
Consultation with Ophthalmologic Surgeon				
Consultation with Orthopedic Surgeon				

Section C.

C1. In general, to what extent are waiting times a problem in your region/district for each of the following? (1=Not a problem at all, 2=Occasionally a problem, 3=Usually a problem, 4=Always a problem, 5=Don't know, 6=Not applicable)

- ☐ Magnetic Resonance Imaging
- ☐ Coronary artery bypass graft surgery
- ☐ Hip/knee surgery
- ☐ Cataract surgery
- ☐ Radiation Oncology
- ☐ Non-urgent out-patient psychiatric treatment
- ☐ Consultations with Cardiac surgeons
- ☐ Consultations with Ophthalmologic surgeons
- ☐ Consultations with Orthopedic surgeons
- ☐ Consultations with Psychiatrists

C2. If waiting lists are a problem in your region/district, how important are each of the following factors in triggering action to solve these problems? (1=Not at all important, 2=Somewhat important, 3=Important, 4=Very important, 5=Don't know)

- ☐ Reports in the media
- ☐ Complaints from the public/patients
- ☐ Monitoring of waiting list data
- ☐ Complaints from physicians/surgeons
- ☐ Complaints from provincial ministries
- ☐ Complaints from elected officials
- ☐ Other, please specify _____

C3. In general, how important are the following factors in determining **how long** people are on waiting lists in your region/district? (1=Not at all important, 2=Somewhat important, 3=Important, 4=Very important, 5=Don't know)

- ☐ Inadequate resources to meet real needs
- ☐ There are incentives to increase waiting list times
- ☐ there are more effective procedures than there used to be
- ☐ Patients are more inclined to undergo treatment than they used to
- ☐ People are placed on lists well in advance of when they really need service
- ☐ The allocation of resources such as Operating Room time to surgeons doesn't match the distribution of "real" demand for surgeons
- ☐ People are unaware that they can get faster service from other surgeons/physicians
- ☐ The waiting lists aren't managed well
- ☐ Waiting may be beneficial for the patient condition
- ☐ Patient preference to defer service
- ☐ Other, please specify _____

C4. In comparison with three years, ago, the waiting time for people requiring the following services has:
(1=Greatly increased, 2=Increased, 3=Decreased, 4=Greatly decreased, 5=Don't know, 6=Not applicable)

- ☐ Magnetic Resonance Imaging
- ☐ Coronary artery bypass graft surgery
- ☐ Hip/knee surgery
- ☐ Cataract surgery
- ☐ Radiation Oncology
- ☐ Non-urgent out-patient psychiatric treatment
- ☐ Consultations with Cardiac surgeons
- ☐ Consultations with Ophthalmologic surgeons
- ☐ Consultations with Orthopedic surgeons
- ☐ Consultations with Psychiatrists

C5. Do you have specific criteria that signal when you should take action to reduce or lengthen waiting list(s) for the following? (please put a check mark in all the cells that apply)

PROCEDURE	CRITERIA							
	No, have no criteria	Volume (number of patients)	Length of waiting time for procedure	Changes in morbidity /mortality rates among people waiting	Est-ablished clinical guide-lines or bench-marks	Other (specify)	Don't know	Not Applicable
Magnetic Resonance Imaging								
Coronary artery bypass graft surgery								
Hip/knee surgery								
Cataract surgery								
Non-urgent out-patient psychiatric treatment								
Radiation oncology								
Consultation with Cardiac surgeon								
Consultation with Psychiatrist								
Consultation with Ophthalmologic Surgeon								
Consultation with Orthopedic Surgeon								

C6. In your view, what is the **most important** purpose of waiting lists? (check only one)

- ☐ To allocate resources to physicians/surgeons
- ☐ To monitor and ensure the fairest possible access to services for patients
- ☐ To allocate resources among institutions and/or departments
- ☐ To prioritize patients
- ☐ To assess adequacy of supply or capacity
- ☐ Other, (please specify) _____
- ☐ Don't know

Section D. WAITING LIST QUALITY AND FUTURE NEEDS

D1. In the following areas how confident are you that your waiting list data accurately represent the need for the following services? (1=Not at all confident, 2=Somewhat confident, 3=Confident, 4=Very confident, 5=Don't know, 6=Not applicable)

- ___ Magnetic Resonance Imaging
- ___ Coronary artery bypass graft surgery
- ___ Hip/knee surgery
- ___ Cataract surgery
- ___ Radiation Oncology
- ___ Non-urgent out-patient psychiatric treatment
- ___ Consultations with Cardiac surgeons
- ___ Consultations with Ophthalmologic surgeons
- ___ Consultations with Orthopedic surgeons
- ___ Consultations with Psychiatrists

D2. To what extent do you think that waiting lists in your region are subject to various 'gaming strategies' (manipulation such as inflating lists with low-need cases, overstating the urgency of patients' circumstances, or suggesting absence of service alternatives) in the following? (1=Never, 2= Occasionally, 3=Often, 4=Always, 5=Don't know, 6=Not applicable)

- ___ Magnetic Resonance Imaging
- ___ Coronary artery bypass graft surgery
- ___ Hip/knee surgery
- ___ Cataract surgery
- ___ Radiation Oncology
- ___ Non-urgent out-patient psychiatric treatment
- ___ Consultations with Cardiac surgeons
- ___ Consultations with Ophthalmologic surgeons
- ___ Consultations with Orthopedic surgeons
- ___ Consultations with Psychiatrists

D5. How would you rate the quality of waiting list information in your own region/district for each of the following services? (1=Excellent, 2=Good, 3=Fair, 4=Poor, 5=Don't know, 6=Not Applicable)

PROCEDURE	DIMENSION of QUALITY		
	Completeness (are data adequate to inform clinical decisions, for planning, monitoring and evaluation)	Standardization (are data consistent and comparable across departments and/or physicians)	Timeliness (are data available when needed to inform clinical decisions and planning)
Magnetic Resonance Imaging			
Coronary artery bypass graft surgery			
Hip/knee surgery			
Cataract surgery			
Non-urgent out-patient psychiatric treatment			
Radiation oncology			
Consultation with Cardiac surgeon			
Consultation with Psychiatrist			
Consultation with Ophthalmologic Surgeon			
Consultation with Orthopedic Surgeon			

D6. What information would better allow you to manage waiting lists?

D7. How much control do you think your health authority can exercise over the time people spend on waiting lists?

☐ None
 ☐ Little
 ☐ Moderate
 ☐ Considerable
 ☐ Complete

D8. Should we require additional information on your region's responses, whom should we contact?

1) Name _____
Organization _____
Address _____

Email _____
Fax _____
Phone _____

2) Name _____
Organization _____
Address _____

Email _____
Fax _____
Phone _____

Please return this questionnaire by March 6, 1998.

Mail to: Dr. Paul McDonald
Health Services Utilization and Research Commission
or Box 46, 103 Hospital Drive
Saskatoon, SK. S7N 0W8
FAX to: FAX: 306-655-1462

To submit your response over the Internet, visit the project website at:

<http://www.sdh.sk.ca/regionalwlq>

APPENDIX 3.B

Cover Letter and Questionnaire Sent to Hospitals



HEALTH SERVICES UTILIZATION AND RESEARCH COMMISSION

Box 46 103 Hospital Drive • Saskatoon, Saskatchewan S7N 0W8
Telephone: (306) 655-1500 • Fax: (306) 655-1462

February 5, 1998

Dear:

We are writing to request your help to examine health service waiting lists in Canada. The current absence of dispassionate and comprehensive information about the state of waiting lists is a substantial impediment to an accurate portrayal of our health care system. In association with Drs. Morris Barer and Sam Sheps of the University of British Columbia and Dr. Sam Shortt of Queen's University, the Health Services Utilization and Research Commission of Saskatchewan (HSURC) is undertaking a national survey of hospitals, regional health authorities and cancer centres to collect objective data on the nature and quality of health service waiting lists.

HSURC is an arms-length, provincially funded government agency with a mandate to assess the health system and recommend evidence-based changes. The research project is being funded by Health Canada and has been endorsed by the Canadian Health Care Association and the Canadian Nursing Association.

The enclosed questionnaire is part of a broader initiative aimed at increasing our understanding of waiting list circumstances and uses. Other project activities include a review of the literature, a survey of professional and consumer associations, as well as interviews with key officials in provincial and territorial Ministries of Health. HSURC is responsible for collecting and analyzing the enclosed survey. Since it is not feasible to collect data on all types of health services, we are limiting our inquiry to a representative group of diagnostic and treatment services. Anonymous, aggregated survey results will be used by the three research teams to prepare a report to Health Canada and for publication in scholarly journals.

Your assistance in completing the questionnaire will help ensure our results are as comprehensive and accurate as possible. We are interested in obtaining your organization's corporate view, and would ask that the survey be directed to and completed by those who can respond on your collective behalf.

In order to provide a preliminary report to Health Canada by the end of their fiscal year, we request that you forward your response **before March 6, 1998**. The survey may be completed and sent over the Internet in either English or French **by logging on to our project website at <http://www.sdh.sk.ca/hospitalwlq>**. If you choose to complete the survey over the Internet, you **must** enter your **Survey Number** located at the top right hand corner of the first page of the paper questionnaire. Alternatively, hard copies of the survey may be faxed (306-655-1462) or mailed to the Principal Investigator for the Saskatchewan site, Paul McDonald, at Box 46 - 103 Hospital Drive, Saskatoon, SK. S7N 0W8. If you received both English and French versions of the questionnaire and you have elected to submit your response by fax or mail, please forward only one copy in the language of your choice. For the convenience of those who have not returned their questionnaire, we will provide a telephone reminder near the due date.

Study results will be posted on the HSURC Website (<http://www.sdh.sk.ca/hsurc/>) after April 17, 1998. If you have any questions or concerns about the enclosed survey, or our project in general, please contact Dr. Paul McDonald at 1-800-655-1599 or mcdonaldp@sdh.sk.ca.

Sincerely,

J. Stewart McMillan, MB, ChB, CCFP, FCFP
Chair

Steven Lewis
CEO and Project Co-investigator

Please respond with your most recent data, preferably 1997

RESPONSES REQUIRED BY MARCH 6, 1998.

SURVEY NUMBER

Section A. GENERAL HOSPITAL INFORMATION

A1. Your hospital is located within what health region/district?

in the province/territory of: _____

A2. What is the population of the health region/district to the nearest 1000, where your hospital is located? _____

A3. Is your hospital formally affiliated with a medical school (i.e., a teaching hospital)?

☐ Yes ☐ No

A4. Check the statement below that best describes your hospital (check only one item):

- ☐ Overall, most of the services our hospital provides are for residents from **within** our health region/ district.
- ☐ Overall, most of the services our hospital provides are for residents from **outside** our health region/ district.
- ☐ Overall, our hospital provides about the same amount of services to residents from inside our health region/district as for outside residents.

A5. Does your health region/district/province have targets for bed utilization rates? ☐ Yes ☐ No

If Yes, your utilization rates are:

_____ acute care patient-days per 1000 population per year (excluding psychiatry and rehabilitation)

_____ physician visits per 1000 population per year

_____ acute psychiatric care beds per 1000 population per year

Section B. CURRENT WAITING LIST DATA and CIRCUMSTANCES

B1. Does your hospital maintain waiting lists for scheduled procedures or consultations? (e.g., Magnetic Resonance Imaging, elective surgery, out-patient psychiatry, radiation oncology, consultations with physician specialists)

☐ Yes (go to next question, B2.)

☐ No

→ If no, skip through to Section C

B2. What type of information is collected by your hospital for the following procedures? (put a check mark in all cells that apply)

PROCEDURE	TYPE OF INFORMATION						
	Patient Demographics	Categories to designate Urgent/ Elective	Physician/ Surgeon who performs the procedure or who patient visits	Diagnosis	Other	Don't Know	Not Applicable
Magnetic Resonance Imaging							
Coronary artery bypass graft surgery							
Hip/knee surgery							
Cataract surgery							
Non-urgent out-patient psychiatric treatment							
Radiation oncology							
Consultation with Cardiac surgeon							
Consultation with Psychiatrist							
Consultation with Ophthalmologic Surgeon							
Consultation with Orthopedic Surgeon							

B3. For each category below, indicate when a person is considered to have been entered on a waiting list: (1=When referred to surgeon/specialist for examination, 2=When decision for surgery/treatment has been made, 3= When hospital is notified with a booking request, 4=Other (please specify), 5=Don't know, 6=Not applicable)

- ___ Magnetic Resonance Imaging
- ___ Coronary artery bypass graft surgery
- ___ Hip/knee surgery
- ___ Cataract surgery
- ___ Radiation Oncology
- ___ Non-urgent out-patient psychiatric treatment

B4. Please provide information on your hospital waiting lists for each of the following procedures during 1997: *(Waiting time is the interval of time between the notification to book a surgery or service until the date the procedure or service has been performed).*

	Average time (weeks) on waiting list	Median time (weeks) on waiting list	Average number of people on waiting list (per week)	Don't know	Not Applicable
Magnetic Resonance Imaging					
Coronary artery bypass graft surgery					
Hip/knee surgery					
Cataract surgery					
Non-urgent out- patient psychiatric treatment					
Radiation Oncology					
Consultation with Cardiac surgeon					
Consultation with Psychiatrist					
Consultation with Ophthalmologic Surgeon					
Consultation with Orthopedic Surgeon					

B5. Within your hospital, who is primarily responsible for making decisions about resource allocation, and prioritizing patients based on waiting list data for the following procedures? (1=Individual physicians/surgeons, 2=Individual departments, 3=Facility administrators, 4=Regional/district administrators, 5=Provincial Ministry/Department of Health, 6=Other, 7=Don't know, 8=Not applicable)

PROCEDURE	Resource Allocation	Prioritizing Patients
Magnetic Resonance Imaging		
Coronary artery bypass graft surgery		
Hip/knee surgery		
Cataract surgery		
Non-urgent out-patient psychiatric treatment		
Radiation oncology		
Consultation with Cardiac surgeon		
Consultation with Psychiatrist		
Consultation with Ophthalmologic Surgeon		
Consultation with Orthopedic Surgeon		

B6. Are you using any structured evaluation method to assess the appropriateness of performing a procedure (e.g., use of clinical practice guidelines, InterQual, etc.)?

PROCEDURE	Yes	No	Don't Know	Not Applicable
Magnetic Resonance Imaging				
Coronary artery bypass graft surgery				
Hip/knee surgery				
Cataract surgery				
Non-urgent out-patient psychiatric treatment				
Radiation oncology				
Consultation with Cardiac surgeon				
Consultation with Psychiatrist				
Consultation with Ophthalmologic Surgeon				
Consultation with Orthopedic Surgeon				

B7. Please indicate how waiting list data are used in your hospital for each of the following procedures:
(please put a check mark in all the cells that apply)

PROCEDURE	PURPOSE						
	Prioritize patients according to their need	Reallocate resources within a department (e.g., between Orthopedic surgeons)	Reallocate resources across departments	Acquire new resources from outside the Hospital's budget	Other	Don't know	Not Applicable
Magnetic Resonance Imaging							
Coronary artery bypass graft surgery							
Hip/knee surgery							
Cataract surgery							
Non-urgent out-patient psychiatric treatment							
Radiation oncology							
Consultation with Cardiac surgeon							
Consultation with Psychiatrist							
Consultation with Ophthalmologic Surgeon							
Consultation with Orthopedic Surgeon							

Section C.

- C1. In general, to what extent are waiting times a problem in your hospital for each of the following:
(1=Not a problem at all, 2=Occasionally a problem, 3=Usually a problem, 4=Always a problem,
5=Don't know, 6=Not applicable)

☐ Magnetic Resonance Imaging
☐ Coronary artery bypass graft surgery
☐ Hip/knee surgery
☐ Cataract surgery
☐ Radiation Oncology
☐ Non-urgent out-patient psychiatric treatment
☐ Consultations with Cardiac surgeons
☐ Consultations with Ophthalmologic surgeons
☐ Consultations with Orthopedic surgeons
☐ Consultations with Psychiatrists

- C2. If waiting lists are a problem in your hospital, how important are each of the following factors in triggering action to solve these problems? (1=Not at all important, 2=Somewhat important, 3=Important, 4=Very important, 5=Don't know)

☐ Reports in the media
☐ Complaints from the public/patients
☐ Monitoring of waiting list data
☐ Complaints from physicians/surgeons
☐ Complaints from provincial ministries
☐ Complaints from elected officials
☐ Other, please specify _____

- C3. In general, how important are the following factors in determining **how long** people are on waiting lists in your hospital? (1=Not at all important, 2=Somewhat important, 3=Important, 4=Very important, 5=Don't know)

☐ Inadequate resources to meet real needs
☐ There are incentives to increase waiting list times
☐ There are more effective procedures than there used to be
☐ Patients are more inclined to undergo treatment than they used to be
☐ People are placed on lists well in advance of when they really need service
☐ The allocation of resources such as Operating Room time to surgeons doesn't match the distribution of "real" demand for surgeons
☐ People are unaware that they can get faster service from other surgeons/physicians
☐ The waiting lists aren't managed well
☐ Waiting may be beneficial for the patient condition
☐ Patient preference to defer service
☐ Other, please specify _____

C4. In comparison with three years ago, the waiting time for people requiring the following services has:
 (1=Greatly increased, 2=Increased, 3=Decreased, 4=Greatly decreased, 5=Don't know, 6=Not applicable)

- ☐ Magnetic Resonance Imaging
- ☐ Coronary artery bypass graft surgery
- ☐ Hip/knee surgery
- ☐ Cataract surgery
- ☐ Radiation Oncology
- ☐ Non-urgent out-patient psychiatric treatment
- ☐ Consultations with Cardiac surgeons
- ☐ Consultations with Ophthalmologic surgeons
- ☐ Consultations with Orthopedic surgeons
- ☐ Consultations with Psychiatrists

C5. Do you have specific criteria that signal when you should take action to reduce or lengthen waiting list(s) for the following? (please put a check mark in all the cells that apply)

PROCEDURE	CRITERIA							
	Have no criteria	Volume (number of patients)	Length of waiting time for procedure	Changes in morbidity/mortality rates among people waiting	Established clinical guidelines or benchmarks	Other (specify)	Don't know	Not applicable
Magnetic Resonance Imaging								
Coronary artery bypass graft surgery								
Hip/knee surgery								
Cataract surgery								
Non-urgent out-patient psychiatric treatment								
Radiation oncology								
Consultation with Cardiac surgeon								
Consultation with Psychiatrist								
Consultation with Ophthalmologic Surgeon								
Consultation with Orthopedic Surgeon								

C6. In your view, what is the **most important** purpose of waiting lists? (check only one)

- ☐ To allocate resources to physicians/surgeons
- ☐ To monitor and ensure the fairest possible access to services for patients
- ☐ To allocate resources among institutions and/or departments
- ☐ To prioritize patients
- ☐ To assess adequacy of supply or capacity
- ☐ Other, (please specify) _____
- ☐ Don't know

Section D. WAITING LIST QUALITY AND FUTURE NEEDS

D1. In the following areas how confident are you that your waiting list data accurately represent the need for the following services? (1=Not at all confident, 2=Somewhat confident, 3=Confident, 4=Very confident, 5=Don't know, 6=Not applicable)

- ___ Magnetic Resonance Imaging
- ___ Coronary artery bypass graft surgery
- ___ Hip/knee surgery
- ___ Cataract surgery
- ___ Radiation Oncology
- ___ Non-urgent out-patient psychiatric treatment
- ___ Consultations with Cardiac surgeons
- ___ Consultations with Ophthalmologic surgeons
- ___ Consultations with Orthopedic surgeons
- ___ Consultations with Psychiatrists

D2. To what extent do you think that waiting lists in your hospital are subject to various 'gaming strategies' (manipulation such as inflating lists with low-need cases, overstating the urgency of patients' circumstances, or suggesting absence of service alternatives) in the following? (1=Never, 2= Occasionally, 3=Often, 4=Always, 5=Don't know, 6=Not applicable)

- ___ Magnetic Resonance Imaging
- ___ Coronary artery bypass graft surgery
- ___ Hip/knee surgery
- ___ Cataract surgery
- ___ Radiation Oncology
- ___ Non-urgent out-patient psychiatric treatment
- ___ Consultations with Cardiac surgeons
- ___ Consultations with Ophthalmologic surgeons
- ___ Consultations with Orthopedic surgeons
- ___ Consultations with Psychiatrists

D3. Where you believe a genuine access problem exists, how effective would each of the following be in reducing waiting list lengths and times? (1 =Very effective, 2=Effective, 3=No effect, 4=Detrimental, 5=Very detrimental, 6=Don't know)

- ☐ Increase supply of hospital beds
- ☐ Increase supply of physicians/surgeons
- ☐ Increase supply of equipment (e.g., MRI's, Radiology equipment)
- ☐ Improve methods for maintaining waiting lists
- ☐ Improve methods for structuring waiting lists
- ☐ Increase supply of Operating Room time
- ☐ Pool waiting lists across facilities
- ☐ Pool waiting lists across regions
- ☐ Develop guidelines for monitoring patients for service
- ☐ Reduce the number of physicians/surgeons
- ☐ Change physician payment system
- ☐ Change public attitudes
- ☐ Change physician attitudes
- ☐ Change the method of funding programs
- ☐ Standardize assessment procedures to determine service needs
- ☐ Other, please specify_____

D4. From what you know about your own and others' waiting list systems and data, how would you rate the quality of waiting list information in Canada overall?

- ☐ Excellent ☐ Good ☐ Fair ☐ Poor ☐ Don't know

D5. How would you rate the quality of waiting list information in your own hospital for each of the following services: (1=Excellent, 2=Good, 3=Fair, 4=Poor, 5=Don't know, 6=Not Applicable)

PROCEDURE	DIMENSION of QUALITY		
	Completeness (are data adequate to inform clinical decisions, for planning, monitoring and evaluation)	Standardization (are data consistent and comparable across departments and/or physicians)	Timeliness (are data available when needed to inform clinical decisions and planning)
Magnetic Resonance Imaging			
Coronary artery bypass graft surgery			
Hip/knee surgery			
Cataract surgery			
Non-urgent out-patient psychiatric treatment			
Radiation oncology			
Consultation with Cardiac surgeon			
Consultation with Psychiatrist			
Consultation with Ophthalmologic Surgeon			
Consultation with Orthopedic Surgeon			

D6. What information would better allow you to manage waiting lists?

D7. How much control do you think your hospital can exercise over the time people spend on waiting lists?

☐ None
 ☐ Little
 ☐ Moderate
 ☐ Considerable
 ☐ Complete

D8. Should we require additional information on your hospital's responses, whom should we contact?

1) Name _____
Organization _____
Address _____

Email _____
Fax _____
Phone _____

2) Name _____
Organization _____
Address _____

Email _____
Fax _____
Phone _____

Please return this questionnaire by March 6, 1998.

Mail to: Dr. Paul McDonald
Health Services Utilization and Research Commission
or Box 46, 103 Hospital Drive
Saskatoon, SK. S7N 0W8
FAX to: FAX: 306-655-1462

To submit your response over the Internet, visit the project website at:

<http://www.sdh.sk.ca/hospitalwlq>

APPENDIX 3.C

Cover Letter and Questionnaire Sent to Provincial Cancer Agencies



HEALTH SERVICES UTILIZATION AND RESEARCH COMMISSION

Box 46 103 Hospital Drive • Saskatoon, Saskatchewan S7N 0W8
Telephone: (306) 655-1500 • Fax: (306) 655-1462

February 5, 1998

Dear:

We are writing to request your help to examine health service waiting lists in Canada. The current absence of dispassionate and comprehensive information about the state of waiting lists is a substantial impediment to an accurate portrayal of our health care system. In association with Drs. Morris Barer and Sam Sheps of the University of British Columbia and Dr. Sam Shortt of Queen's University, the Health Services Utilization and Research Commission of Saskatchewan (HSURC) is undertaking a national survey of hospitals, regional health authorities and cancer centres to collect objective data on the nature and quality of health service waiting lists.

HSURC is an arms-length, provincially funded government agency with a mandate to assess the health system and recommend evidence-based changes. The research project is being funded by Health Canada and has been endorsed by the Canadian Health Care Association and the Canadian Nursing Association.

The enclosed questionnaire is part of a broader initiative aimed at increasing our understanding of waiting list circumstances and uses. Other project activities include a review of the literature, a survey of professional and consumer associations, as well as interviews with key officials in provincial and territorial Ministries of Health. HSURC is responsible for collecting and analyzing the enclosed survey. Since it is not feasible to collect data on all types of health services, we are limiting our inquiry to a representative group of diagnostic and treatment services. Anonymous, aggregated survey results will be used by the three research teams to prepare a report to Health Canada and for publication in scholarly journals.

Your assistance in completing the questionnaire will help ensure our results are as comprehensive and accurate as possible. We are interested in obtaining your organization's corporate view, and would ask that the survey be directed to and completed by those who can respond on your collective behalf. Please note that the term cancer centre is meant to include specialized cancer treatment centres, provincial cancer agencies and cancer registries. It does not include general hospitals that provide cancer treatment.

In order to provide a preliminary report to Health Canada by the end of their fiscal year, we request that you forward your response **before March 6, 1998**. The survey may be faxed (306-655-1462) or mailed to the Principal Investigator for the Saskatchewan site, Paul McDonald, at Box 46 - 103 Hospital Drive, Saskatoon, SK. S7N 0W8. If you received both English and French versions of the questionnaire, please forward only one copy in the language of your choice. For the convenience of those who have not returned their questionnaire, we will provide a telephone reminder near the due date.

Study results will be posted on the HSURC Website (<http://www.sdh.sk.ca/hsurc/>) after April 17, 1998. If you have any questions or concerns about the enclosed survey, or our project in general, please contact Dr. Paul McDonald at 1-800-655-1599 or mcdonaldp@sdh.sk.ca.

Sincerely,

J. Stewart McMillan, MB, ChB, CCFP, FCFP
Chair

Steven Lewis
CEO and Project Co-investigator



WAITING LIST QUESTIONNAIRE to be completed by CANCER AGENCIES

Please respond with your most recent data, preferably 1997

RESPONSES REQUIRED BY MARCH 6, 1998.

SURVEY NUMBER

Section A. WAITING LIST CIRCUMSTANCES

Central waiting list registries in the section below refers to a compilation of waiting list information that is mandated and maintained by a province and housed in a central place designated by the province.

A1. Does your province maintain a central waiting list for scheduled procedures or consultations (e.g., Magnetic Resonance Imaging, elective surgery, radiation oncology, consultations with physician specialists)?

☐ Yes (go to next question, A2.)

☐ No

→ If no, do some other groups or agencies maintain waiting list registries that you routinely use or have access to?

☐ Yes (go to next question, A2.)

☐ No



If no, skip through to Section B

A2. If a central waiting list registry is maintained, what role does your agency perform? (check all that apply)

- ☐ Monitor waiting list data compiled and provided by others, (e.g. hospitals, cancer clinics)
- ☐ Actively collect and update waiting list data
- ☐ Use waiting list data to manage resources
- ☐ Analyze data
- ☐ Coordinate between lists/services/clinics
- ☐ Other (please specify) _____

A3. What type of information is collected by your agency for the following services? (put a check mark in all cells that apply)

PROCEDURE	TYPE OF INFORMATION						
	Patient Demographics	Categories to designate Urgent/ Elective	Physician/ Surgeon who performs the procedure or who patient visits	Diagnosis	Other	Don't Know	Not Applicable
Radiation oncology							
Consultation with Radiation Oncologist							

- A4. For each category below, indicate when a person is considered to have been entered on a waiting list: (1=When referred to surgeon/specialist for examination, 2=When decision for surgery/treatment has been made, 3= When clinic is notified with a booking request, 4=Other (please specify), 5=Don't know, 6=Not applicable)

___ Radiation Oncology
___ Consultation with an Radiation Oncologist

- A5. Please provide information on your agency's waiting lists for each of the following procedures during 1997: (*Waiting time is the interval of time between the notification to book a service until the date the service starts*).

	Average time (weeks) on waiting list	Median time (weeks) on waiting list	Average number of people on waiting list (per week)	Don't know	Not Applicable
Radiation Oncology					
Consultation with Radiation Oncologist					

- A6. Within your province, who is primarily responsible for making decisions about resource allocation, and prioritizing patients based on waiting list data for the following services? (1=Individual physicians/surgeons, 2=Individual departments within cancer clinics, 3=Facility administrators within clinics, 4=Regional/district administrators, 5=Provincial Ministry/Department of Health, 6=Staff at the Cancer Registry, 7=Other, 8=Don't know, 9=Not applicable,)

PROCEDURE	Resource Allocation	Prioritizing Patients
Radiation oncology		
Consultation with Radiation Oncologist		

- A7. Does your province consistently use any structured evaluation method to assess the appropriateness of performing a procedure (e.g. Committee on Standards of the Canadian Association of Radiation Oncologists or other clinical practice guidelines)

PROCEDURE	Yes	No	Don't Know	Not Applicable
Radiation oncology				
Consultation with Radiation Oncologist				

B5. Do you have specific criteria that signal when you should take action to reduce or lengthen waiting list(s) for the following? (please put a check mark in all the cells that apply)

PROCEDURE	CRITERIA							
	No, have no criteria	Volume (number of patients)	Length of waiting time for procedure	Changes in morbidity/mortality rates among people waiting	Est- ablished clinical guide- lines or bench- marks	Other (specify)	Don't know	Not applicable
Radiation oncology								
Consultation with Radiation Oncologist								

B6. In your view, what is the **most important** purpose of waiting lists? (check only one)

- ☐ to allocate resources to physicians/surgeons
☐ to monitor and ensure the fairest possible access to services for patients
☐ to allocate resources among institutions and/or departments
☐ to prioritize patients
☐ to assess adequacy of supply or capacity
☐ other, (please specify) _____
☐ don't know

Section C. WAITING LIST QUALITY AND FUTURE NEEDS

C1. In the following areas how confident are you that your waiting list data accurately represent the need for the following services? (1=Not at all confident, 2=Somewhat confident, 3=Confident, 4=Very confident, 5=Don't know, 6=Not applicable)

___ Radiation Oncology
 ___ Consultations with Radiation Oncologist

C2. To what extent do you think that waiting lists in your agency are subject to various 'gaming strategies' (manipulation such as inflating lists with low-need cases, overstating the urgency of patients' circumstances, or suggesting absence of service alternatives) in the following? (1=Never, 2= Occasionally, 3=Often, 4=Always, 5=Don't know, 6=Not applicable)

___ Radiation Oncology
 ___ Consultations with Radiation Oncologists

C3. Where you believe a genuine access problem exists, how effective would each of the following be in reducing waiting list lengths and times? (1 =Very effective, 2=Effective, 3=No effect, 4=Detrimental 5=Very detrimental 6=Don't know)

- ___ increase supply of hospital beds
- ___ increase supply of physicians/surgeons
- ___ increase supply of technicians
- ___ increase supply of qualified medical physicists
- ___ increase supply of equipment (e.g., MRI's, Radiology equipment)
- ___ improve methods for maintaining waiting lists
- ___ improve methods for structuring waiting lists
- ___ increase supply of Operating Room time
- ___ pool waiting lists across facilities
- ___ pool waiting lists across regions
- ___ develop guidelines for monitoring patients for service
- ___ reduce the number of physicians/surgeons
- ___ change physician payment system
- ___ change public attitudes
- ___ change physician attitudes
- ___ change the method of funding programs
- ___ standardize assessment procedures to determine service needs
- ___ other, please specify _____

C4. From what you know about your own and others' waiting list systems and data, how would you rate the quality of waiting list information in Canada overall?

- ☐ Excellent ☐ Good ☐ Fair ☐ Poor ☐ Don't know

C5. How would you rate the quality of waiting list information in your own agency for each of the following services: (1=Excellent, 2=Good, 3=Fair, 4=Poor, 5=Don't know, 6=Not Applicable)

	DIMENSION of QUALITY		
PROCEDURE	completeness (are data adequate to inform clinical decisions, for planning, monitoring and evaluation)	standardization (are data consistent and comparable across departments and/or physicians)	timeliness (are data available when needed to inform clinical decisions and planning)
Radiation oncology			
Consultation with Radiation Oncologist			

C6. What information would better allow you to manage waiting lists?

C7. ☐ How much control ☐ you think you ☐ agency can exercise ☐ over the time people spend on waiting lists?

None Little Moderate Considerable Complete

C8. Should we require additional information on your agency's responses, whom should we contact?

1) Name _____
Organization _____
Address _____

Email _____
Fax _____
Phone _____

2) Name _____
Organization _____
Address _____

Email _____
Fax _____
Phone _____

Please return this questionnaire by March 6, 1998.

Mail to: Dr. Paul McDonald
Health Services Utilization and Research Commission
or Box 46, 103 Hospital Drive
Saskatoon, SK. S7N 0W8
FAX to: FAX: 306-655-1462

APPENDIX 3.D

Cover Letter and Questionnaire Sent to Cancer Clinics and Treatment Centres

Your assistance in completing the questionnaire will help ensure our results are as comprehensive and accurate as possible. We are interested in obtaining your organization's corporate view, and would ask that the survey be directed to and completed by those who can respond on your collective behalf. Please note that the term cancer centre is meant to include specialized cancer treatment centres, provincial cancer agencies and cancer registries. It does not include general hospitals that provide cancer treatment.

In order to provide a preliminary report to Health Canada by the end of their fiscal year, we request that you forward your response **before March 6, 1998**. The survey may be completed and sent over the Internet in either English or French **by logging on to our project website at <http://www.sdh.sk.ca/cancerwlq>**. If you choose to complete the survey over the Internet, you **must** enter your **Survey Number** located at the top right hand corner of the first page of the paper questionnaire. Alternatively, hard copies of the survey may be faxed (306-655-1462) or mailed to the Principal Investigator for the Saskatchewan site, Paul McDonald, at Box 46 - 103 Hospital Drive, Saskatoon, SK. S7N 0W8. If you received both English and French versions of the questionnaire and you have elected to submit your response by fax or mail, please forward only one copy in the language of your choice. For the convenience of those who have not returned their questionnaire, we will provide a telephone reminder near the due date.

Study results will be posted on the HSURC Website (<http://www.sdh.sk.ca/hsurc/>) after April 17, 1998. If you have any questions or concerns about the enclosed survey, or our project in general, please contact Dr. Paul McDonald at 1-800-655-1599 or mcdonaldp@sdh.sk.ca.

Sincerely,

J. Stewart McMillan, MB, ChB, CCFP, FCFP
Chair

Steven Lewis
CEO and Project Co-investigator



WAITING LIST QUESTIONNAIRE to be completed by **CANCER CLINICS**

Please respond with your most recent data, preferably 1997

RESPONSES REQUIRED BY MARCH 6, 1998.

SURVEY NUMBER

Section A. CLINIC INFORMATION

A1. Your clinic/treatment centre is located within what health region/district?

in the province/territory of: _____

A2. What is the population of the health region/district to the nearest 1000, where your clinic or treatment centre is located? _____

A3. Is your clinic or treatment centre formally affiliated with a medical school?

Yes ☐ No ☐

A4. Check the statement below that best describes your clinic or treatment centre (check only one item):

- ☐ Overall, most of the services our clinic provides are for residents from **within** our health region/ district.
- ☐ Overall, most of the services our clinic provides are for residents from **outside** our health region/ district.
- ☐ Overall, our clinic provides about the same amount of services to residents from inside our health region/district as for outside residents.

Section B. CURRENT WAITING LIST DATA and CIRCUMSTANCES

B1. Does your clinic or treatment centre maintain waiting lists for scheduled procedures or consultations? (e.g., Magnetic Resonance Imaging, radiation oncology, consultations with oncologists)

☐ Yes (go to next question, **B2.**)

☐ No

→ If no, skip through to **Section C**

B2. What type of information is collected by your clinic for the following services? (put a check mark in all cells that apply)

PROCEDURE	TYPE OF INFORMATION						
	Patient Demographics	Categories to designate Urgent/ Elective	Physician/ Surgeon who performs the procedure or who patient visits	Diagnosis	Other	Don't Know	Not Applicable
Radiation oncology							
Consultation with Radiation Oncologist							

- B3.** For each category below, indicate when a person is considered to have been entered on a waiting list:
(1=When referred to surgeon/specialist for examination, 2=When decision for surgery/treatment has been made, 3= When clinic is notified with a booking request, 4=Other (please specify), 5=Don't know, 6=Not applicable)

___ Radiation Oncology
___ Consultation with an Radiation Oncologist

- B4.** Please provide information on your clinic waiting lists for each of the following procedures during 1997: (*Waiting time is the interval of time between the notification to book a service until the date the service starts*).

	Average time (weeks) on waiting list	Median time (weeks) on waiting list	Average number of people on waiting list (per week)	Don't know	Not Applicable
Radiation Oncology					
Consultation with Radiation Oncologist					

- B5.** Within your clinic or treatment centre, who is primarily responsible for making decisions about resource allocation, and prioritizing patients based on waiting list data for the following services?
(1=Individual physicians/surgeons, 2=Individual departments, 3=Facility administrators, 4=Regional/district administrators, 5=Provincial Ministry/Department of Health, 6=Other, 7=Don't know, 8=Not applicable)

PROCEDURE	Resource Allocation	Prioritizing Patients
Radiation oncology		
Consultation with Radiation Oncologist		

- B6.** Are you using any structured evaluation method to assess the appropriateness of performing a procedure (e.g. Committee on Standards of the Canadian Association of Radiation Oncologists or other clinical practice guidelines)

PROCEDURE	Yes	No	Don't Know	Not Applicable
Radiation oncology				
Consultation with Radiation Oncologist				

Section C.

C1. In general, to what extent are waiting times a problem in your clinic or treatment centre for each of the following: (1=Not a problem at all, 2=Occasionally a problem, 3=Usually a problem, 4=Always a problem, 5=Don't know, 6=Not applicable).

- ☐ Radiation Oncology
- ☐ Consultations with Radiation Oncologists

C2. If waiting lists are a problem in your clinic or treatment centre, how important are each of the following factors in triggering action to solve these problems? (1=Not at all important, 2=Somewhat important, 3=Important, 4=Very important, 5=Don't know)

- ☐ reports in the media
- ☐ complaints from the public/patients
- ☐ monitoring of waiting list data
- ☐ complaints from physicians/surgeons
- ☐ complaints from provincial ministries
- ☐ complaints from elected officials
- ☐ other, please specify _____

C3. In general, how important are the following factors in determining how long people are on waiting lists in your clinic or treatment centre? (1=Not at all important, 2=Somewhat important, 3=Important, 4=Very important, 5=Don't know)

- ☐ inadequate resources/equipment to meet real needs
- ☐ there are incentives to increase waiting list times
- ☐ there are more effective procedures than there used to be
- ☐ patients are more inclined to undergo treatment than they used to be
- ☐ people are placed on lists well in advance of when they really need service
- ☐ the allocation of resources doesn't match the distribution of "real" demand for services
- ☐ people are unaware that they can get faster service from other surgeons/physicians
- ☐ the waiting lists aren't managed well
- ☐ supply of qualified Oncologists
- ☐ supply of technicians
- ☐ waiting may be beneficial for the patient condition
- ☐ patient preference to defer service
- ☐ other, please specify _____

C4. In comparison with three years ago, the waiting time for people requiring the following services has: (1=Greatly increased, 2=Increased, 3=Decreased, 4=Greatly decreased, 5=Don't know, 6=Not applicable)

- ☐ Radiation Oncology
- ☐ Consultations with Radiation Oncologists

C5. Do you have specific criteria that signal when you should take action to reduce or lengthen waiting list(s) for the following? (please put a check mark in all the cells that apply)

PROCEDURE	CRITERIA							
	No, have no criteria	Volume (number of patients)	Length of waiting time for procedure	Changes in morbidity/mortality rates among people waiting	Established clinical guidelines or benchmarks	Other (specify)	Don't know	Not applicable
Radiation oncology								
Consultation with Radiation Oncologist								

C6. In your view, what is the **most important** purpose of waiting lists? (check only one)

- ☐ to allocate resources to physicians/surgeons
☐ to monitor and ensure the fairest possible access to services for patients
☐ to allocate resources among institutions and/or departments
☐ to prioritize patients
☐ to assess adequacy of supply or capacity
☐ other, (please specify) _____
☐ don't know

Section D. WAITING LIST QUALITY AND FUTURE NEEDS

D1. In the following areas how confident are you that your waiting list data accurately represent the need for the following services? (1=Not at all confident, 2=Somewhat confident, 3=Confident, 4=Very confident, 5=Don't know, 6=Not applicable)

- _____ Radiation Oncology
 _____ Consultations with Radiation Oncologist

D2. To what extent do you think that waiting lists in your clinic or treatment centre are subject to various 'gaming strategies' (manipulation such as inflating lists with low-need cases, overstating the urgency of patients' circumstances, or suggesting absence of service alternatives) in the following? (1=Never, 2= Occasionally, 3=Often, 4=Always, 5=Don't know, 6=Not applicable)

- _____ Radiation Oncology
 _____ Consultations with Radiation Oncologists

D7. How much control do you think your clinic or treatment centre can exercise over the time people spend on waiting lists?

☐ None ☐ Little ☐ Moderate ☐ Considerable ☐ Complete

D8. Should we require additional information on your clinic or treatment centre's responses, whom should we contact?

1) Name _____
Organization _____
Address _____

Email _____
Fax _____
Phone _____

2) Name _____
Organization _____
Address _____

Email _____
Fax _____
Phone _____

Please return this questionnaire by March 6, 1998.

Mail to: Dr. Paul McDonald
Health Services Utilization and Research Commission
or Box 46, 103 Hospital Drive
Saskatoon, SK. S7N 0W8
FAX to: FAX: 306-655-1462

To submit your response electronically, visit the project website at:
<http://www.sdh.sk.ca/cancerwlq>

APPENDIX 3.E

Reminder Card Sent to All Sites

HEALTH SERVICES UTILIZATION AND RESEARCH COMMISSION

Box 46 103 Hospital Drive • Saskatoon, Saskatchewan S7N 0W8

Telephone: (306) 655-1500 • Fax: (306) 655-1462

February 25, 1998

Dear Colleague:

We recently sent you a survey designed to increase our understanding of waiting list circumstances and uses. If you have already forwarded your response, please accept our thanks. If you have not yet returned our questionnaire, please accept this reminder that responses are required on or before March 6, 1998. Completed questionnaires may be returned by mail, fax, or through the internet.

If you have any questions about the survey, or you require additional copies, please contact the Principal Investigator for the project, Paul McDonald, at 306-655-1505 or mcdonaldp@sdh.sk.ca.

Yours sincerely,

J. Stewart MacMillan, M.B., Ch.B., C.C.F.P. **Steven Lewis**
HSURC Chair **CEO**

CEO

APPENDIX 3.F

Script of Telephone Follow-up to Non-responsive Sites

Hello, my name is _____ and I'm a research officer with the Health Services Utilization and Research Commission. We are an arms length government agency in Saskatchewan that has been contracted by Health Canada to collect objective information on health service waiting lists. A few weeks ago we mailed you a survey to inquire about the waiting list situation within your hospital/regional health district/cancer centre. The purpose of the survey is to help us develop an accurate picture of the waiting list situation across the country. It asked whether you collect or have access to waiting list information for a sample of health service. It also asked your opinions about the situation in Canada.

1. Did you receive the survey?

Yes (go to 2)

No (May I fax you a copy? Fax number _____)

Forwarded to colleagues (Name and telephone _____)

Don't know

Other _____

1. Have you completed the survey and sent it in?

Yes (We appreciate your help, terminate call)

No

Don't know

Other _____

1. Do you intend to fill it out and send it in?

Yes (Just a reminder that it is required by March 27th at the latest; terminate call)

No

Don't know

1. To help guide our future research, may I briefly inquire why you will be unable to complete the survey? (check all that apply)

Do not have sufficient time or personnel

Survey was too long

Have misplaced survey

Concern about how the data will be used/concern about purpose of study

Do not see waiting list as an important issue

Survey isn't relevant to organization due to restructuring

Survey isn't relevant to organization because it does not provide the service identified

Survey isn't relevant to organization because it does not collect data/maintain lists

Survey isn't relevant to organization - other _____

Other _____

Survey number:

Organization name, province and region:

APPENDIX 3.G
Names and Location of Survey Respondents

NAME	City	Province	Organization
Cape Breton Regional Hospital	Sydney	NS	Hospital
Dartmouth General Hospital and Community Health Centre	Dartmouth	NS	Hospital
The Moncton Hospital	Moncton	NB	Hospital
Edmundston Regional Hospital	Edmundston	NB	Hospital
Centre hospitalier et centre de rAdaptation Antoine Labelle	Des Rivières	QC	Hospital
Centre hospitalier rJgional du SuroTt	Valleyfield	QC	Hospital
Centre hospitalier de la RJgion de l'Amiante	Thetford	QC	Hospital
Centre hospitalier rJgional de Sept-Iles	Sept-Iles	QC	Hospital
H^pital Laval	Sainte-Foy	QC	Hospital
Centre hospitalier Le Gardeur Inc.	Repentigny	QC	Hospital
H^pital Notre-Dame de Fatima	La PocatiPre	QC	Hospital
Centre hospitalier de Lachine	Lachine	QC	Hospital
H^pital Charles LeMoyne	Greenfield	QC	Hospital
H^tel-Dieu d'Arthabaska	Victoriaville	QC	Hospital
H^pital d'Amqui	Amqui	QC	Hospital
Centre hospitalier H^tel-Dieu d'Amos	Amos	QC	Hospital
The Northumberland Health Care Corporation	Cobourg	ON	Hospital
North York Branson Hospital	North York	ON	Hospital
Women's College Hospital	Toronto	ON	Hospital
Toronto East General and Orthopaedic Hospital	Toronto	ON	Hospital
Sunnybrook Health Science Centre	North York	ON	Hospital
St. Joseph's Health Centre	Toronto	ON	Hospital
Mount Sinai Hospital	Toronto	ON	Hospital
Timmins and District Hospital	Timmins	ON	Hospital
Stratford General Hospital	Stratford	ON	Hospital
Norfolk General Hospital	Simcoe	ON	Hospital
Scarborough General Hospital	Scarborough	ON	Hospital
St. Joseph's Health Centre of Sarnia	Sarnia	ON	Hospital
St. Catharines General Hospital, The	St. Catharines	ON	Hospital

Hotel Dieu Hospital	St. Catharines	ON	Hospital
York Central Hospital	Richmond Hill	ON	Hospital
St. Joseph's Hospital & Health Centre	Peterborough	ON	Hospital
Pembroke General Hospital	Pembroke	ON	Hospital
West Parry Sound Health Centre	Parry Sound	ON	Hospital
Grey Bruce Regional Health Centre, The	Owen Sound	ON	Hospital
Oshawa General Hospital	Oshawa	ON	Hospital
North Bay General Hospital - Scollard St. Site	North Bay	ON	Hospital
York County Hospital	Newmarket	ON	Hospital
Queensway-Carleton Hospital	Nepean	ON	Hospital
Ross Memorial Hospital	Lindsay	ON	Hospital
St. Mary's General Hospital	Kitchener	ON	Hospital
Hotel Dieu Hospital	Kingston	ON	Hospital
Lake of the Woods District Hospital	Kenora	ON	Hospital
Queensway General Hospital	Etobicoke	ON	Hospital
Hotel Dieu Hospital	Cornwall	ON	Hospital
Joseph Brant Memorial Hospital	Burlington	ON	Hospital
Brockville General Hospital	Brockville	ON	Hospital
Peel Memorial Hospital	Brampton	ON	Hospital
Memorial Hospital	Bowmanville	ON	Hospital
Belleville General Hospital	Belleville	ON	Hospital
Royal Victoria Hospital	Barrie	ON	Hospital
Ajax and Pickering General Hospital	Ajax	ON	Hospital
Dufferin-Caledon Health Care Corporation	Orangeville	ON	Hospital
Swift Current Regional Hospital	Swift Current	SK	Hospital
Lloydminster Hospital	Lloydminster	SK	Hospital
St. Joseph's Hospital	Estevan	SK	Hospital
Victoria General Hospital	Winnipeg	MB	Hospital
Seven Oaks General Hospital	Winnipeg	MB	Hospital
Salvation Army Grace General Hospital, The	Winnipeg	MB	Hospital
Misericordia General Hospital	Winnipeg	MB	Hospital
Pas Health Complex Inc., The	The Pas	MB	Hospital
Rimbey Hospital and Care Centre (H)	Rimbey	AB	Hospital

Medicine Hat Regional Hospital	Medicine Hat	AB	Hospital
Lamont Health Care Centre (H)	Lamont	AB	Hospital
Innisfail Health Centre	Innisfail	AB	Hospital
Foothills Provincial General Hospital	Calgary	AB	Hospital
Trail Regional Hospital	Trail	BC	Hospital
Surrey Memorial Hospital	Surrey	BC	Hospital
Prince George Regional Hospital	Prince George	BC	Hospital
Powell River General Hospital	Powell River	BC	Hospital
Nanaimo Regional General Hospital	Nanaimo	BC	Hospital
Langley Memorial Hospital	Langley	BC	Hospital
Kelowna General Hospital	Kelowna	BC	Hospital
St. Joseph's General Hospital	Comox	BC	Hospital
Campbell River & District General Hospital	Campbell River	BC	Hospital
Montréal Children's Hospital, The	Montréal	QC	pediatric
The Hospital for Sick Children	Toronto	ON	pediatric
Tom Baker Cancer Centre	Calgary	AB	Clinic
Cross Cancer Institute	Edmonton	AB	Clinic
Grande Prairie Cancer Centre	Grande Prairie	AB	Clinic
Northeastern Ontario Regional Cancer Centre	Sudbury	ON	Clinic
Windsor Regional Cancer Centre	Windsor	ON	Clinic
Manitoba Cancer Treatment & Research Foundation	Winnipeg	MB	Clinic
Allan Blair Cancer Centre	Regina	SK	Clinic
Cancer Care Nova Scotia	Halifax	NS	Clinic
Newfoundland Cancer Treatment and Research Foundation	St. John's	NF	Clinic
Department of Oncology	St. John	NB	Clinic
L. Dumont Regional Hospital	Moncton	NB	Clinic
East Muskoka/Parry Sound District Health Council	Huntsville	ON	Region
Haldimand-Norfolk District Health Council	Townsend	ON	Region
Hastings & Prince Edward Counties	Belleville	ON	Region
Kent County District Health Council	Chatham	ON	Region
Kingston, Frontenac and Lennox, and	Kingston	ON	Region
Metro Toronto District Health Council	Willowdale	ON	Region
Niagara District Health Council	Fonthill	ON	Region

Peel District Health Council	Brampton	ON	Region
Simcoe County District Health Council	Barrie	ON	Region
Thunder Bay District Health Council	Thunder Bay	ON	Region
Waterloo Region District Health Council	Waterloo	ON	Region
Région régionale de la santé et des services sociaux	Trois-Rivières	QC	Region
Région régionale de la santé et des services sociaux	Hull	QC	Region
Région régionale de la santé et des services sociaux	Rouyn-Noranda	QC	Region
Région régionale de la santé et des services sociaux	Joliette	QC	Region
Health Labrador Corporation	Happy Valley		
	/Goose Bay	NF	Region
Central West Health Board	Grand Falls		
	/Windsor	NF	Region
Community Health Western	Corner Brook	NF	Region
Southern Kings Health Region	Montague	PE	Region
Eastern Kings Health Region	Souris	PE	Region
South-East Health Care Corporation	Moncton	NB	Region
Corporation hospitalière Beauséjour Hospital Corporation	Moncton	NB	Region
Nor'Est/Nor'East Health Network	Bathurst	NB	Region
Region 3 Hospital Corporation	Fredericton	NB	Region
Restigouche Health Services Corporation	Campbellton	NB	Region
Brandon Regional Health Authority	Brandon	MB	Region
Parkland Regional Health Authority Inc.	Dauphin	MB	Region
Assiniboine Valley Health District	Kamsack	SK	Region
North Valley Health District	Melville	SK	Region
North-East Health District	Nipawin	SK	Region
North Central Health District	Melfort	SK	Region
Pasquia Health District	Tisdale	SK	Region
Touchwood Qu'Appelle Health Board	Fort Qu'Appelle	SK	Region
Pipestone Health District	Grenfell	SK	Region
Moose Mountain Health District	Wawota	SK	Region
South Country Health District	Assiniboia	SK	Region
Mamawetan/Munito Health Board	La Ronge	SK	Region
Parkland Health District	Spiritwood	SK	Region

Gabriel Springs Health District	Rosthern	SK	Region
Greenhead Health District	Unity	SK	Region
Prairie West Health District	Kindersley	SK	Region
Midwest Health District	Outlook	SK	Region
Keewatin-Yathe Health Board	Buffalo	SK	Region
Southwest Health District	Shaunavon	SK	Region
East Central Health District	Yorkton	SK	Region
South East Health District	Estevan	SK	Region
Moose Jaw-Thunder Creek Health District	Moose Jaw	SK	Region
Battlefords Health District	North Battleford	SK	Region
Swift Current Health District	Swift Current	SK	Region
Rolling Hills Health District	Swift Current	SK	Region
Lloydminster Health District	Lloydminster	SK	Region
Lakeland Regional Health Authority (#12)	Smoky Lake	AB	Region
Westview Regional Health Authority (#8)	Devon	AB	Region
Northwestern Health Services Region (#17)	High Level	AB	Region
David Thompson Health Region (#6)	Red Deer	AB	Region
East Central Regional Health Authority (#7)	Camrose	AB	Region
Capital Health Authority (#10)	Edmonton	AB	Region
Peace Health Region (#14)	Peace River	AB	Region
Simon Fraser Health Region	New Westminster	BC	Region
Central Vancouver Island Health Region	Nanaimo	BC	Region
Baffin Regional Health Board	Iqaluit	NT	Region
Keewatin Regional Health Board	Ranklin Inlet	NT	Region
Deh Cho Health & Social Services Board	Fort Simpson	NT	Region
British Columbia Cancer Agency			
– Vancouver Island Cancer Centre	Victoria	BC	Agency
British Columbia Cancer Agency - Vancouver Cancer Centre	Vancouver	BC	Agency
Alberta Cancer Board	Edmonton	AB	Agency
Saskatchewan Cancer Agency	Saskatoon	SK	Agency
Cancer Care Ontario	Toronto	ON	Agency

Chapter 4:

Attitudes and Activities Related to Waiting Lists for Medical Services in Canada: A Survey of Provider, Administrative, and Consumer Groups

**S.E.D.Shortt, M.D., Ph.D
B. Douglas Ford, M.A.
Queen's Health Policy
Queen's University
Kingston, Ontario**

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EXECUTIVE SUMMARY

This study was designed to describe attitudes towards and activities related to waiting for medical services in Canada on the part of non-governmental organizations representing consumers, administrators, and providers.

One hundred and nine Canadian non-governmental organizations, representing 34 consumer groups, 57 provider groups, and 18 administrative organizations, were selected to participate in a semi-structured telephone survey.

The response rate was 68%. On a 4 point Likert scale the over-all importance rating assigned to waiting issues was 3.5. Slightly less than ½ the groups actively contributed to or monitored waiting lists. Members of this subset of groups were unanimous that waits were excessive, that they had lengthened over the preceding 5 years, and would likely do so over the next five. Clinical need was seen as the appropriate method to allocate waiting places and clinical evidence the essential criteria for defining excessive waits. The poor, elderly, rural dwellers and socially disadvantaged groups were seen as the Canadians most adversely affected by waiting lists. Inadequate funding, an aging population, and poor management of current resources were seen as the major causes of increased waiting lists. Enhanced funding and improved coordination of resources were considered the most appropriate interventions.

This study established that waiting times for medical services are viewed as an important issue by relevant Canadian non-governmental organizations. The key issues concern equity, funding, information needs, and coordination of resource allocation procedures.

1.0 Introduction

Medicare has long been recognized as a cherished social institution in Canada. Increasingly, however, Canadians are expressing concerns that the quality or availability of services are deteriorating. Waiting times are a case in point. Polls conducted by the Angus Reid Group on behalf of the Canadian Medical Association in 1997 found, for example, that 63% of respondents reported waiting times for surgery had worsened, up from 53% in 1996 (Angus Reid Group, 1997). These perceptions may be, in part, the product of exposure to the media which is quick to report on tragic outcomes for patients waiting unsuccessfully for hospital admission or emergency care. They may also be validated by the well-reported annual publication on Canadian waiting times by the Fraser Institute. For 1996 it wrote: "Not only were there approximately 11 percent more people waiting for treatment than there were in 1995, but those waiting were waiting longer..." (Ramsay et al., 1997, p.1). Finally, public perceptions may be based on both personal experience and objective reality. Whatever the origin of such convictions, however, rising public concern about waiting times for medical services clearly merits further investigation. It is this belief which motivates the present study.

2.0 Objectives

This study was designed to elicit in-depth information from a cross-section of relevant groups representing Canadian health care consumers, providers and administrators. Specifically it sought:

- ▶ details of any activities related to the maintenance or study of waiting lists; and
- ▶ opinions and attitudes toward various aspects of waiting lists

3.0 Definitions

A *waiting list* is a roster of patients awaiting a specific health service. Such lists refer to elective rather than emergency services, though some lists may be kept for urgent services as well.

Waiting time refers to the length of time a patient spends on a particular list awaiting the desired service. (This differs from the patient's *entire* waiting experience which begins with the onset of symptoms and ends with either receipt of the relevant diagnostic or therapeutic intervention or removal from the list for various reasons).

4.0 Study Design

- ▶ Semi-structured telephone interviews

5.0 Respondents

The subjects were selected as follows:

- ▶ A search of health services literature was done using Medline and HealthStar, supplemented by a manual search, to identify Canadian health services for which waiting times appeared to be of concern. The list was refined in consultation with five health services researchers from across Canada.
- ▶ Prospective respondents were divided into three broad categories:
 1. **Providers** - This term is used to describe organizations of professionals, such as physiotherapists, physicians, or nurses.
 2. **Administrators** - This label refers largely to hospital associations or umbrella organizations for institutions and other facilities. Explicitly excluded were provincial government officials, regional health authority employees, and administrators of individual hospitals, all of whom were to be contacted in two companion surveys.
 3. **Consumers** - Groups in this category included either direct consumer organizations or organizations run on behalf of consumers of a specific service.

- ▶ A matrix was created in which organizations under the three group categories were matched by their principal interest to the services identified as associated with concerns about waiting [Table 4.1].
- ▶ This process produced a list of 109 potential respondents. For a variety of reasons displayed in Table 4.2, 35 groups were unable or declined to participate. They are listed in Appendix 4.A and the groups which did participate are listed in Appendix 4.B. The geographical distribution of participants is given in Table 4.3. It will be seen from the table that Quebec is relatively under-represented in terms of province-specific groups, though the province does share representation within national organizations.

Table 4.1: Selection Matrix for Survey Candidates

Topic / Groups	Consumers	Providers	Admin. *
coronary surgery	7	1	-
cataract surgery	2	2	-
knee/hip replace.	3	7	-
radiation oncology	4	2	-
MRI	-	1	-
community mental health	1	4	1
general systemic issues	11	36	16
other	6	4	1
Totals	34	57	18

(* excludes federal, provincial & regional authority staff)

Table 4.2: Reasons for Non-participation by Group

Reason	Number		
	Cons	Prov	Ad
No explanation / other	1	-	2
Outside organizational area of interest	5	2	-
No detailed knowledge of waiting issues	1	4	2
Unable to contact or schedule interview	6	9	3
Total	35		

Table 4.3: Geographic Distribution of Subjects (*1 association represents 2 regions)

Region/Assoc.	Admin.	Consumer	Provider	Totals
National	3	13	18	34
Nfld & L	1	-	2	3
Nova Scotia	-	1	1	2
New Brunswick	1	-	1	2
PEI	-	-	2	2
Quebec	1	-	1	2
Ontario	2	4	7	13
Manitoba	-	-	1	1
Sask.	-	-	2	2
Alberta	1	1	2	4
BC	1	2	4	7
NWT	1	-	-	1
Yukon	-	1	1	2
Totals	11	22*	42	75*

6.0 Methods

Senior officials in the target groups were contacted by telephone in January, 1998 and the study was explained. They were then asked to identify the person in their organization best suited to respond. In most instances the individual contacted initially, often the executive director or president of the group, served as the respondent for the survey. A convenient time was arranged to conduct the interview and a respondent version of the Waiting Issues Questionnaire (WIQ) [Appendix 4.C] was faxed immediately so as to allow the interviewee an opportunity to formulate responses, collect data, or confer with colleagues. No incentives for participation were offered, though respondents were given the opportunity to receive an executive summary of the study if they so wished.

The WIQ was developed to gather information about activities related to and opinions about waiting times. It was created following an extensive review of the Canadian and international literature to identify the key issues related to waiting times and lists. Items 1 to 8 elicited information about waiting lists for which the organization actively collected data or with which it was closely familiar. Items 9 to 17 gathered organizational ideas about or attitudes towards waiting lists. Organizations which did not collect data on waiting proceeded directly to item 9. The interviewer version [Appendix 4.D] differed from the respondent version in that the preamble of the latter was replaced by a section in which to record particulars of the interview (e.g. date, respondent, organization).

The WIQ was administered by one experienced interviewer (B.F.) several days to several weeks after receipt of the faxed instrument. The semi-structured interview required on average one half hour to complete, with a range from 15 minutes to 75 minutes.

7.0 Results

7.1 Response Rate

Of the 109 organizations targeted, interviews were completed with 74, yielding a 67.9% response rate. The number of respondents and percentage response rate by group were as follows: providers 42 (73.7%), consumers 21 (61.8%), and administrators 11 (61.1%).

7.2 Importance of Waiting Lists

The key informants were asked to rate the importance of waiting-related issues in health care. The four-point Likert scale went from '1. Not at all important' to '4. Very important.' The overall average was 3.5. The mean for administrative organizations was 3.2 with a standard deviation (sd) of 0.6, 3.6 for consumer groups (with a sd of 0.6), and 3.5 for provider associations (with a sd of 0.7). There was no significant difference between these means. These findings indicate waiting issues are viewed by most respondents as quite important for contemporary Canadian health care.

7.3 Involvement with Waiting Lists and Issues

Despite a consensus on the importance of waiting issues in Canadian health care, the level of concrete activity by the surveyed groups was limited. This was evident in three areas:

- ▶ When asked whether their organization was familiar with specific waiting lists or participated in the creation of lists, less than half the groups responded in the affirmative. The positive responses by group were: administrators 3/11, consumers 11/21, and providers 22/42.
- ▶ Almost none of the groups had undertaken any detailed study of waiting lists or times (though several had participated in studies done by others and several planned future research).
- ▶ Few groups could point to other specific actions which they had taken to deal with issues related to waiting. Among the administrative groups, 3 indicated lobbying government on waiting issues, as did a number of consumer and provider groups.

Patient education and data gathering was also mentioned by a number of groups. However, among consumer groups 9 of 21 took no form of action, while 10 of 42 provider groups were similarly inactive.

7.4 Existing Lists

Thirty-six of the surveyed groups were aware of or contributed to lists. Only one respondent stated unequivocally that the waiting time on their list was acceptable. A large majority stated waiting times five years earlier were less, and the majority also envisaged increased waiting times five years hence. The specific responses by service type of provider groups are tabulated in Appendix 4.E and of consumers in Appendix 4.F.

Lists referred to by the 3 administrative groups were created in various ways. However, most respondents from the other two groups indicated the lists with which they were familiar were a product of a combination of patient need, clinical evidence of appropriate intervention and order in which patients were entered by physicians. The majority of respondents felt these criteria were appropriate, though providers felt enhanced evidence-based guidelines and centralized list formation would improve existing lists.

7.5 Defining Excessive Waits

Administrative groups felt excessive waits were best defined by evidence-based measures of clinical urgency. Consumer groups generally agreed that clinical need was the appropriate decision tool but often stated this need should incorporate an appreciation of quality of life issues. The provider group offered the most detailed range of criteria for identifying excess waiting. They felt that the risk of deterioration in clinical status and quality of life, coupled with an ability to benefit from the proposed intervention, provided a basis for decision making. Many groups also commented on two other relevant factors: the need for public input and the need to consider the cost of resources necessary to provide the service.

7.6 Groups Most Affected by Waiting Lists

There was a clear consensus that poor and elderly patients were the most likely to experience adverse effects from waiting. The former were unable to access private care if available and lacked skills necessary to navigate successfully the public system; the latter were likely to suffer from disorders requiring services for which there were queues. Rural residents were also viewed as experiencing a disproportionate waiting burden because of poorly distributed services. As well, groups deemed socially disadvantaged, such as aboriginal peoples, the disabled or the mentally ill, and the families of patients, were frequently mentioned as adversely affected by waiting lists.

7.7 Causes of Waiting Lists

Respondents were asked to rank order nine possible causes of wait lists. The average ranking of these factors by association type are presented in Table 4.4. As will be seen inadequate funding was ranked first overall by representatives of administrative, consumer and provider healthcare associations, and least equivocally by the latter. For consumer group respondents aging of the population tied inadequate funding for first place and healthcare provider shortages was ranked third.

Table 4.4: Mean Ranking Of Possible Waiting List Causes

Possible Causes of Waiting Lists	Mean Rankings*		
	Admin.	Consumer	Provider
Change in disease patterns	6	5.3	6.7
Health care provider shortages	6.9	4.5	5.1
Aging population	6.9	3.4	4.3
Hospital Restructuring	6.3	6	4.6
Poor management of current resources	5.2	5.9	5.8
Patient expectations	6.9	7.8	6.7
Restricted access to technology	5.6	6.5	6.5
Inadequate funding	4.6	3.4	2.9
Past failure to invest in prevention	7.1	5.7	6.3

(*1= most important; 9 = least important)

Aging of the population was second for provider key informants and hospital restructuring was third. Poor management of current resources and restricted access to technology were ranked second and third respectively by subjects representing administrative organizations.

7.8 Recommended Government Actions

Two administrative groups out of 11 suggested increased funding was the appropriate response from government, while 7 suggested better coordination or monitoring of lists. Among the 21 consumer groups, 10 advised increased funding and 9 recommended improved coordination or data gathering. Of the 42 provider groups, 13 recommended increased funding, 9 supported improved coordination and planning, and 7 suggested enhanced community care would relieve pressure on services or facilities for which waits existed.

8.0 Discussion

All respondents considered waiting times an important issue. Most respondents familiar with specific lists considered their length excessive and predicted continued deterioration in the level of service. These opinions must be placed in the context of the literature on waiting lists which suggests that while lists may express demand, they are a poor reflection of actual need. For example, audits of lists in the United Kingdom reveal a sizable proportion of patients who do not belong in the queue or no longer require the service (Hochuli, 1988; Roy and Hunter, 1996). As well, many lists are entered on a first come, first served basis, a system which fails to accurately capture the relative need of dissimilar patients. Finally, there is substantial variation amongst physicians in the criteria used to undertake procedures (Naylor and Jaglal, 1993), suggesting there is often no consensus on the definition of clinical need. While waiting lists for some services in Canada may be growing, this is not necessarily a sign that the system is failing to meet legitimate needs.

Respondents emphasized the importance of using evidence-based clinical criteria to prioritize patients on waiting lists and to define maximum acceptable waiting times for specific services. The Ontario experience since 1991 in operating a province-wide priority-based registry for patients

awaiting coronary artery bypass grafting provides evidence that such a process does, indeed, enhance the provision of medical services. As with a similar program in New Zealand, Ontario physicians were accepting both of the process and result of guideline formation (Hadorn and Holmes, 1997; Naylor et al, 1992). An evaluation of the early performance of the system concluded that, despite some inequitable variation between hospitals, queuing patients rarely experienced critical cardiac events or extreme delays, and variations in individual waiting times reflected primarily clinical acuity (Naylor et al, 1995). It is important to acknowledge, however, that for many other clinical conditions the precise consequences of waiting are unknown. Only recently, for example, has evidence begun to accumulate on the impact of waiting on clinical topics such as the quality of life and function for joint replacement candidates (Williams et al, 1997) or the prospects for successful control of local tumor spread (Mackillop et al., 1996). In the absence of such studies, prioritization based on widely accepted evidence is best viewed as a future goal rather than a present possibility.

Interview respondents revealed considerable agreement that waiting lists exerted a disproportionate impact on the poor and the elderly. In reference to the latter, many of the services for which there are waiting lists, including cataract surgery, hip and knee replacement, or radiation oncology therapy, are services consumed largely by the elderly. However, the perception that the economically disadvantaged pay an unfair price must be balanced by an appreciation of what the Canadian system of health care offers those with few resources. Some degree of waiting is endemic to state-funded, universal-access health systems. Consumers, in effect, “pay” only by the time they spend waiting for a service. In contrast, the entrepreneurial American system is distinguished by competition amongst providers who, in order to eliminate waits, must maintain costly excess capacity. In this system services are rationed by price and millions of Americans lack the financial resources even to join a queue for medical care (Naylor, 1991). Waiting for services, then, appears to be the price that Canadians must pay for the privilege of universal access unrelated to economic circumstances.

Many respondents recommended that the system collect accurate data on waiting times and suggested that the adoption of centralized management of lists would foster more efficient

distribution of scarce resources. With the exception of cardiac surgery, there is little doubt that the Canadian health care system generally suffers from both a paucity of waiting time data and inefficient decentralization of list management. A 1992 study of British Columbia secondary and tertiary care institutions revealed that in 10 of 17 hospitals lists were compiled in the offices of individual surgeons and in 13 of 17 institutions the decision as to the next patient to be admitted was made entirely by individual surgeons. None of the hospitals had guidelines for compiling or using waiting list data and none coordinated their lists with nearby institutions (Amoko et al., 1992). Given the success of efforts to manage cardiac surgery in Ontario and other provinces (Cox et al., 1996; Kieser et al., 1995; Hartford and Roos, 1995) through centralized data collection and list management, it seems reasonable to begin to apply the same principles to other clinical conditions associated with queuing.

Many respondents blamed increased waiting times on decreased funding and argued that the appropriate policy was to intervene with enhanced funding. Doubtless funding cuts have played a role in lengthening queues for some services, but the general relationship between resource augmentation and length of waiting lists is highly complex. There are examples from the United Kingdom in which list audits and additional resources have successfully reduced lists for general surgery (Parmar, 1993; Harvey et al., 1993), ophthalmology (Lee et al., 1992), and urology (Mobb et al., 1994). Other studies, however, suggest no or transient benefits from additional resources in orthopaedics (Mackinnon et al., 1992), general surgery (Umeh et al., 1994), and ophthalmology (Storror et al., 1989).

Far from reducing waiting times, extra resources may have the opposite effect. A study of surgical services in the Oxford area found that as admissions from the waiting list were expedited, the list increased in length (Goldacre et al., 1989). This phenomenon has been referred to as “feedback” and describes the tendency of family physicians to preferentially increase referrals to services which appear to have shrinking waiting lists, thereby off-setting any gains (Worthington, 1987). As well, it has been shown that adding surgeons to a hospital may initially reduce existing waiting lists but within two years will spawn lists of almost equal size for the new staff member (Frost, 1980). An Australian study has argued that hospital managers who receive extra resources to deal

with waiting lists have little incentive to reduce the lists which brought them enhanced resources (Street and Duckett, 1996). Finally an American study has suggested that funding increased hospital bed capacity in individual hospitals may give rise to precipitously increasing waiting lists when utilization rates increase beyond 90 percent (McQuarrie, 1983). This body of evidence suggests how complex the relationship is between waiting lists and enhanced resources.

The present study has a number of limitations. First, the selection process may not have identified all relevant groups for participation, nor identified the most appropriate spokesperson within each group. It seems likely, however, particularly with a response rate of 68%, that the groups represents an adequate sample of health-related non-governmental organizations in Canada. Since most individual respondents were executive directors or presidents of their organizations, it is reasonable to assume that they were appropriate spokespersons. Nevertheless, the generalizability of the survey to the entire Canadian population of similar groups, agencies or representatives can not be assumed. Secondly, there was evidence of under representation of some geographical areas and of groups concerned with certain types of health services. It is uncertain whether this would significantly alter the study results. Thirdly, some groups were narrowly focused on a single clinical area and were not readily able to venture informed opinion on broad systemic issues, while other groups were conversant only with general issues but lacked experience with specific examples of waiting lists. These distinct orientations may have balanced each other. Finally, there appeared to be a surprising discrepancy between the declared level of importance accorded by respondents to waiting lists and the actual amount of group activity devoted to waiting issues. This may reflect the fact that most waiting list issues are a relatively recent feature of the Canadian health care system, such that few groups have yet had the opportunity to compile data or undertake studies. None of these limitations are likely to have a significant impact on the validity of the findings of the study, since its intent was simply to canvas involvement and views on these issues.

9.0 Conclusion

This study has examined the activities and attitudes of non-governmental organizations in reference to waiting lists for medical services in Canada. Less than half the groups interviewed actively contributed to or were familiar with a specific waiting list, virtually none had produced studies of waiting times, and few had taken any action related to waiting issues beyond lobbying government. Despite this lack of action, there was a consensus that waiting lists were an important issue in Canadian health care. Respondents believed clinical evidence should be used to delineate maximum acceptable waiting times. They felt that the poor, the elderly, and other disadvantaged groups were most adversely affected by lengthy waiting lists. Inadequate resources, an aging population and poor management of current resources were seen as the major causes of increased waiting. Finally, enhanced funding and improved coordination of resource allocation were deemed the most appropriate forms of government intervention. Whatever the objective reality of waiting lists, it is clear from this study that a heterogeneous group of health organizations has identified as the key issues equity, funding, information needs, and coordination of service provision.

APPENDIX 4.A

Groups Unable/Declining to Participate

Administrators

British Columbia, Stroke Recovery
Canadian Institute for Health Information
Manitoba Health Organizations
Nova Scotia Association of Health Organizations
Prince Edward Island Health Association
Saskatchewan Association of Health Organizations
Yukon Hospital Association

Consumers

Canadian Adult Congenital Heart Network
Canadian Diabetes Association
Canadian Cardiovascular Society
Canadian Breast Cancer Foundation
Conference Board of Canada
Consumers' Association of Canada
Easter Seals, March of Dimes National Council
Gray Panthers
Helped The Aged
Kidney Foundation of Canada
Ontario March of Dimes
Osteoporosis Society of Canada
Senior Link

Providers

Canadian Association of Interns and Residents
Canadian Mental Health
Association
Canadian Orthopaedic Association
Canadian Public Health
Association
College of Family Physicians of Canada
Manitoba Association of Registered Nurses
New Brunswick Nurses Association
Northwest Territories Medical Association
Northwest Territories Registered Nurses Association
Nova Scotia Medical Society
Ontario Medical Association
Ontario Psychological Association
Ontario Registered Nurses Association
Physiotherapy Foundation of Canada
Yukon Medical Association

APPENDIX 4.B

Participating Groups

Providers

Alberta Association of Registered Nurses
Alberta Medical Association
Association of Nurses of Prince Edward Island
Association of Registered Nurses of Newfoundland
British Columbia Medical Association
British Columbia Physiotherapy Association
British Columbia Transplant Society
Canadian Anaesthetists' Society
Canadian Association of General Surgeons
Canadian Association of Physical Medicine & Rehabilitation
Canadian Association of Radiation Oncologists
Canadian Association of Radiologists
Canadian Implant Association
Canadian Medical Society
Canadian Nurses Association
Canadian Ophthalmological Society
Canadian Paediatric Society
Canadian Palliative Care Association
Canadian Physiotherapy Association
Canadian Psychiatric Association
Canadian Psychological Association
Canadian Society of Cardiovascular & Thoracic Surgeons
Community Occupational Therapists & Associates
Manitoba Medical Association
Medical Society of Prince Edward Island
Multiple Organ Retrieval & Exchange Program of Ontario
New Brunswick Medical Society
Newfoundland & Labrador Medical Association
Ontario Nurses Association
Ontario Nursing Home Association
Ontario Physiotherapy Association
Ontario Public Health Association
Ontario Residential Care Association
Organ Donors Canada
Quebec Medical Association
Registered Nurses' Association of British Columbia
Registered Nurses' Association of Nova Scotia
Royal College of Physicians & Surgeons of Canada
Saskatchewan Medical Association
Saskatchewan Registered Nurses' Association
Victorian Order of Nurses for Canada (VON)

Yukon Registered Nurses' Association

Administrators

Association des Hôpitaux du Québec
British Columbia Health Association
Canadian College of Health Service Executives
Canadian Health Care Association
New Brunswick Healthcare Association
Newfoundland & Labrador Health Care Association
Northwest Territories Health Care Association
Ontario Hospital Association
Ontario Association of Children's Mental Health Centres
Provincial Health Authorities of Alberta

Consumers

Advanced Coronary Treatment Foundation of Canada
Arthritis Society, The
Breast Cancer Action
Breast Cancer Society of Canada
Canadian Association of Gerontology
Canadian Association of Retired Persons
Canadian Cancer Society
Canadian Council of The Blind
Canadian Hearing Society
Canadian Liver Foundation
Canadian National Institute For The Blind
Canadian Prostate Cancer Foundation
Greater Kingston Area Injured Workers Association
Heart & Stroke Foundation of Alberta
Heart & Stroke Foundation of British Columbia & The Yukon
Heart & Stroke Foundation of Canada
Heart & Stroke Foundation of Nova Scotia
Heart & Stroke Foundation of Ontario
Osteoporosis Society of British Columbia
Schizophrenia Society of Canada
Stroke Recovery Association of Ontario

APPENDIX 4.C
Respondent Questionnaire

WAITING ISSUES QUESTIONNAIRE
VERSION - I

Date Administered:.....
Interviewer:.....
Organization:.....
Contact for Interview:.....
Comments

Question 1

Is your organization aware of any waiting lists for medical services relevant to your interests?

YES

NO

If the answer to Question 1 is NO, then please proceed to Question 9.

(Questions 2 to 8 should be answered separately for each waiting list if your organization has concerns regarding more than one waiting list.)

Question 2.

What is the nature of the waiting list (i.e. bypass, cataract, prostate, etc...)?

Question 3a.

Please estimate the current length of the waiting list.

Question 3b.

What is the current average wait time?

Question 3c.

Is the current average wait time acceptable?

YES

NO

Question 4a.

What was the approximate length of the waiting list five years ago?

Question 4b.

What was the average wait time five years ago?

Question 5a.

Based on present trends, estimate the length of the waiting list five years hence.

Question 5b.

Based on present trends, estimate the average wait time five years hence.

Question 6.

How was this waiting list generated? Please circle only one of the following six choices.

4. Priority based on established clinical evidence.
2. Priority based simply on need.
3. On the basis of first come first served.
4. On the preferences of the allocating authority and the value placed on certain patient characteristics.
5. Some combination of the above. Please specify:
6. Other method. Please specify:

Question 7.

Is this an appropriate method for waiting list generation?

YES

NO

Question 8.

If in control, how would you generate the waiting list?

Please use answer key from Question 6.

The remaining questions pertain to waiting-related issues in general.

Question 9.

Please rank in order the following possible causes of waiting lists from 1 to 10 with 1 being the most important and 10 the least.

- _____ Change in disease prevalence
- _____ Healthcare provider shortages
- _____ Aging of population
- _____ Hospital restructuring
- _____ Poor management of current resources
- _____ Patient expectations
- _____ Restricted access to technology
- _____ Inadequate funding
- _____ Past failure to invest in prevention
- _____ Other. Please specify

Question 10.

Which groups are affected and how by waiting for medical services?

Question 11.

What criteria should be used to decide what constitutes the maximum acceptable wait time?

Question 12.

Has your organization undertaken or does it plan any action specifically designed to address waiting issues? Please specify.

Question 13.

Does your organization have suggestions for how the government should deal with waiting issues?

Question 14.

Taking into consideration the various issues in health care today, how important are waiting issues? Please circle only one response.

1. Not at all important
2. Somewhat important
3. Important

4. Very important

Question 15.

Is or has your group produced any studies of, or position papers on, waiting-related issues?
If so, please provide references.

Question 16.

Is there anyone else you feel we should contact, either in your organization or beyond.

Question 17.

Do you have any additional information or comments with regard to waiting-related issues?

Thank-you for taking the time to share your views and information with us. We at the Queen's University Health Policy Research Unit greatly appreciate your help and that of your organization. Please feel free to contact us at any time if you have additional information for us or believe that we may be of assistance to you.

If you would like an executive summary of the resultant report, please indicate below.

YES

NO

Again, we at Queen's Health Policy thank-you for your participation.

APPENDIX 4.D
Interviewer Questionnaire Preamble
Waiting Issues Questionnaire
(Version - 2)

Date administered

Interviewer

Organization

.....

Contact for interview

.....

Comments

.....

.....

.....

APPENDIX 4.E
Wait Lists With Times Judged Unacceptable By Providers

Wait List	Current Wait Time (Average or Range)	Wait Time Five Years Ago	Projected Wait Time Five Years Hence
Surgery			
Coronary Surgery	6 to 8 months	1 to 2 months	1 year
	12 to 18 months	same	same
	5+ months	shorter	6 to 8 months
	4 months	-	longer
Cataract Surgery	3 weeks to 1 year	shorter	longer
	1 year	3 months	2 years
	6 months	same	same
	1 month to 1 year	-	longer
	2.5 to 5 months	longer	same
Hip/Knee Replacement	up to 2 years	shorter	same
	15 months	-	longer
	5 to 10 months	longer	same
Urgent - cancers, bowel disease	up to 6 weeks	same	longer
General	6 to 8 weeks	-	-
Elective	6 months	1 month	year
Back, disk	3 months	-	longer
Plastic	6 to 18 months	longer	same
Peripheral Vascular surgery			
Inpatient	5 months	longer	same
Day Surgery	9 months	longer	same
Diagnostic Procedures			
MRI	4 to 5 months	shorter	half*
	2 to 4 months	-	longer
CT Scan	6 months	same	half*

	2 to 4 months	-	longer
Mammography	4 to 5 months	no waiting	no waiting
Ultrasound	8 months	shorter	half*
Homecare			
Home Support Workers	weeks to months	longer	longer
Visiting Nursing	weeks to months	no waiting	longer
Psychiatric Services			
Community Mental Health - Alzheimers Day Away Program	weeks to months	shorter	longer
Consultation	54 days	3 weeks	longer
Psychotherapy	unavailable in small centres luck of the draw in large	1 month	longer
Placements in chronic care facilities	180+ days	-	longer
Speciality services: anxiety, depression, eating disorders	6 to 12 months some places unavailable	-	longer
Long-term Care			
	up to 3 years	longer	shorter*
	104.5 days	-	same*
	3 to 6 months	2 to 3 months	6 months
	2 years	same	same
Physiotherapy			
Community	3 weeks to 6 months	3 weeks to 3 months	longer
Outpatient	3 months to year	3 to 6 months	2+ years
Paediatric Services			
Paediatric Services: Psychology, Psychiatry, Speech Therapy, Physiotherapy, O.T., School Problems, Surgery	up to 3 years for some services, increased wait in small centres and rural areas	shorter	longer
Transplants			
Heart	3/4 year	same	longer
	200 days	half	double

	highly variable	same	-
Lung	2+ years	same	longer
	300 days	half	double
Liver	6 months	same	longer
	250 days	half	double
	highly variable	same	-
Kidney	2 years	same	longer
	480 days	half	double
	highly variable	same	-
	28 months	18 to 20 months	longer
Cornea	1 year	2 years	longer
Miscellaneous			
Pallative Care	2 to 3 weeks	same	longer
Radiation Oncology	8 to 10 months	shorter	-
	7 weeks	much shorter	half*
	1 to 6 weeks	-	longer
Dialysis	140 on waiting list - no data- no machines	much shorter	half*

* If proposed government funding materializes

APPENDIX 4.F: Wait Lists With Times Judged Unacceptable By Consumers

Wait List	Current Wait Time (Average or Range)	Wait Time Five Years Ago	Protected Wait Time Five Years Hence
Medical Surgical			
Coronary Surgery	6 to 8 weeks	same	same*
	2 months	same	-
	4 to 9 months	shorter	longer
Pacemaker	"no idea, that's why we are creating a database	shorter	longer
Angioplasty	"no idea, that's why we are creating a database	shorter	longer
Knee/Hip Replacement	1 month to 1 year	-	double
Rheumatologist Appointment	6 weeks	-	longer
Oncology			
Radiation Oncology	-	shorter	shorter
Chemotherapy	-	shorter	shorter
Diagnostic			
Dexa bone density measurement	3 to 4 months	-	double
Mammography	-	shorter	shorter
Bone Marrow	-	shorter	shorter
Mental Health			
Psychiatric Assessment	6+ months	same	longer
Supported Housing or Group Homes	1+ years	same	longer
O.T. Day Program	up to a year	same	longer
Outside Social Workers	2 to 4 months	same	longer
Psychiatric Treatment	6 to 15 weeks	same	longer
Transplant			
Liver Transplant	6 months	-	longer
Liver Specialist	1 month	shorter	same or longer
Vision			
Services for the Blind: Intake Counselling, Rehabilitation, Low Vision Clinic	2 days to 6 months, depends on area	same	shorter
Rehabilitation, Low Vision Clinic	3 to 5 weeks	shorter	longer

* If proposed government funding materializes

Chapter 5:

Health Care Waiting Lists and Waiting Times: A Critical Review of the Literature

Claudia Sanmartin, M.Sc., Ph.D Candidate

Morris L. Barer, MBA, Ph.D

Samuel B. Sheps, M.D., M.Sc., FRCPC

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EXECUTIVE SUMMARY

As waiting lists are continually being blamed for hindering reasonable access to health care services, governments across Canada are being called on by health care professionals and patients to address the issue of waiting lists and waiting times. A more comprehensive understanding of this phenomenon and the factors that affect both wait list size and wait time is required to better inform and direct policy development in this area. The following conclusions are based on a critical review of the published and unpublished literature regarding the nature of waiting lists and waiting times.

Conceptualizations of Waiting Lists

Waiting lists have been defined and conceptualized in various ways including as indicators of unmet need, inadequate resources, misallocated resources, and access to health care as well as mechanisms to ration resources. These conceptualizations are important since they derive from general beliefs regarding the major causes and solutions for waiting lists rather than direct evidence on the existence of presumptive causes or the effectiveness on the implied policy solution. The argument that waiting lists are indicators of underfunding also tend to believe that the only solution is more funding.

Reliability and Validity of Waiting List Data

Information on waiting list size and waiting times is available in some countries through administrative databases and from provider surveys in others. There is a growing concern among researchers and policy-makers regarding the validity and reliability of waiting time data. There is very limited information regarding the validity of waiting time as a measure of time spent on the waiting list. This is due primarily to the range of methods used to determine when the waiting period actually begins. There are a range of methods used (e.g. cross-sectional, retrospective, cohort, expected waiting time, expected waiting time to clear waiting list) which may result in different measures of waiting time. The distributions of waiting times for a given procedure tend to be skewed.

There is similar concern regarding the reliability of waiting list data. The evidence suggests that there may be a degree of inflation in many waiting list size estimates of between 20% and 30%. The generalizability of these results is limited due to limited sample sizes and limited sites of the studies reviewed. The key variable is clearly waiting times since it most directly affects patients; waiting list size is important in so far as it affects patient waiting times.

Factors Affecting Waiting Lists and Waiting Times

Intra-procedure variations in waiting list size and waiting times have been documented at various levels (e.g. physician, hospital, regions). This provides some indication that there may be a range of factors at each level which affect waiting list size and waiting times. The identification of the factors affecting waiting list size and waiting times is important since they represent the policy levers that could be used to effect change. There is very limited empirical evidence regarding the significance of various physician, hospital and regional factors on waiting list size and waiting times. This is due, in part, to a lack of a critical mass of studies required to draw definitive conclusions. There is equally limited information regarding the effect of patient socio-economic and demographic characteristics. Patient clinical status, however, has been shown to affect waiting times when waiting lists are properly managed and prioritized. There are numerous factors, such as the role of patient choice, physician referral patterns, global budgets, hypothesized to affect waiting lists that to date have not been rigorously tested.

We found no general theoretical framework which attempts to outline a comprehensive range of factors that may affect waiting list size and waiting times. The development of such a framework would serve both to identify the range of contributing factors as well as provide some information regarding the pathways through which they affect waiting list size and waiting times. The studies to date have been limited in scope due to the absence of such a framework and limited data. There is clearly a need to promote studies which focus on a broader range of factors simultaneously in multivariate analyses. Waiting lists and waiting times exist in a complex environment affected by various forces at the patient, physician, hospital and regional/provincial level. As such, complex models are required to consider these effects, as well as interactions, simultaneously.

Effects of Waiting Lists

An increasing number of studies are beginning to focus on the effects of waiting lists, specifically effects on patients. Patients awaiting surgery experience various physical effects such as pain, limited mobility and general discomfort. Patients awaiting care may also experience emotional strains such as increased levels of anxiety due to a range of factors including lack of information and uncertainty regarding the timeline for care and the effect of waiting on the outcome of care. There is limited generalizable evidence regarding the prevalence of physical, emotional, and economic burdens experienced by patients or the degree to which they affect patients. The on limited evidence suggests that burdens of waiting for care vary depending on procedure, age, gender, and employment status.

Despite the adverse effects of waiting for care, there is some evidence that patients are not always dissatisfied with waiting. Furthermore, despite some patients feeling waits are “too long”, very few would be prepared to see tax dollars go to reducing wait times, and fewer still seem prepared to pay out-of-pocket to reduce these waits. The research to date has not focussed on the effects of waiting lists on other groups such as informal care givers, health care providers, administrators and governments.

Waiting List Policies

The experiences of the UK, Sweden, Australia, New Zealand and selected Canadian provinces provide valuable lessons regarding policy options for addressing waiting lists and waiting times. There are three general types of policies: (1) monitoring policies ; (2) “supply-side” policies which focus on the delivery of services; and (3) “demand-side” policies which focus on the management of waiting lists. The scope of the policies ranges from local initiatives focussed on a single waiting list to national strategies aimed at reducing waiting times for a whole range of services. The types of policies range from the development of local registries for specific services to national waiting time guarantees. In most cases, multiple policy approaches are adopted simultaneously to address different aspects of a waiting list situation.

Efforts to collect waiting list data range from the establishment of a national administrative database in which hospitals are required to participate, to provider surveys in which hospitals

and physicians are requested to report waiting times and waiting list size. Experiences to date suggest that reliable and valid waiting list data are required to determine the current state of waiting list size and waiting times and to monitor the short and long term effects of various “supply” and “demand” policies. The data should be collected in a consistent and comprehensive manner, with clearly defined and consistently applied criteria for “date on” and “date off”, in order to ensure comparability at various levels (e.g. regions, hospitals), and over time.

There have been various “supply-side” policies adopted to date which focus on increasing the number and type of health care services provided, primarily through increased funding, in order to reduce waiting lists and waiting times. Experience suggests the following:

- ▶ Any additional funding should be specifically targeted to reduce waiting list size and eliminate long waits. This will ensure that the funds are not used for other purposes.
- ▶ Targeted funding can provide short-term relief to reduce backlogs and temporarily clear or reduce waiting lists. This type of policy DOES NOT represent a long-term solution to waiting lists. Increases in admission to care from waiting lists are often followed by an increase in new patients, resulting in an overall *increase* in waiting list size.
- ▶ Targeted funding can provide short-term reductions in waiting times if funds are specifically used to provide services to those patients waiting longer than a specified period of time (e.g. 18 months, 2 years) or to guarantee patients medical care within a specified period of time. Such policies, however, may have a detrimental effect on accessibility to health care if services are provided at the expense of other patients on a list who do not meet the time criteria.
- ▶ Targeted funding DOES NOT necessarily represent a long-term solution to reducing waiting times. In most cases, initial reductions in waiting times are not sustained following a period of additional funding.

- ▶ There is no evidence to suggest that private sector health care will result in shorter waiting lists and waiting times in the public sector. Greater access to private care appears to be generally associated with LONGER public sector queues.

The “demand-side” policies adopted to date have focussed primarily on the management of waiting lists, including the prioritization of patients awaiting medical care through the identification of clinically appropriate criteria.

- ▶ Selection criteria for waiting list placement can be used to ensure that only those patients for whom the services are medically necessary are provided with treatment.
- ▶ Consensus panels can be used to develop procedure-specific criteria for determining priority, as has been done for coronary artery bypass surgery. These criteria serve to ensure that patients are appropriately prioritized and managed while on the waiting list.
- ▶ Consensus panels can also be used to determine acceptable waiting times for specific groups of patients based on clinical and other criteria. This appears to be a valid and reliable method of determining acceptable or reasonable waiting times, if it is evidence-based.
- ▶ While selection and priority criteria can be used to effectively manage and monitor patients on waiting lists, their effect on waiting list size and waiting times has not been thoroughly investigated.

Introduction

In most publicly funded health care systems, waiting lists are widely used as indicators of access to health care services, with implications for individuals, informal care-givers, health care professionals, policy-makers, and governments. For some patients, they may simply represent minor inconveniences. For other patients, however, excessive waiting periods may result in considerable anxiety, adverse health effects and lower quality of life. From a health care provider perspective, waiting lists may represent restricted availability of resources which they deem necessary for the management of their patients. From a broader health care system organization and funding perspective, waiting lists have been viewed as measures or indicators of general accessibility, equity of access and “underfunding”. As waiting lists are increasingly blamed for hindering reasonable access to health care services, governments both across Canada and abroad are being increasingly called on by health care professionals and patients to address the issue of waiting lists and waiting times.

A comprehensive understanding of the nature, extent, and scope of waiting lists is fundamental to the development of effective policy. The results of various research efforts conducted both within Canada and internationally provide some insight regarding the nature of waiting lists and waiting times and the factors that may affect them. Currently, much is assumed but little is actually known about the nature of wait lists and wait times. The debate surrounding waiting lists and how best to address them, therefore, has been and continues to be driven by assumptions and myths regarding the nature of waiting lists. It is for this reason that the policies adopted to date have failed to have any long-term effects. A more comprehensive understanding of this phenomenon and the factors that affect both wait list size and wait time is required to better inform and enhance policy development in this area.

The primary goal of this chapter is to synthesize the information we identified in the published and unpublished literature regarding the nature of waiting lists and waiting times. We canvassed national and international literature for this purpose. The information has been organized around a set of key questions regarding the nature of waiting lists and the policies adopted to date to address them.

1.0 Methodology

This chapter contains a critical review and synthesis of the published and unpublished information regarding waiting lists for health care services in Canada and abroad. This section describes the research strategy used to identify the sources of information and the methods used to critically review the studies identified.

1.1 Search Strategy

Information on waiting lists was sought in both the published and unpublished literature. Search strategies were developed to suit the particular type of literature.

Published Literature

The primary source of original research regarding the nature of waiting lists and waiting times was published journals and books. Empirical studies were identified using the following medical and social science databases:

MEDLINE: includes all published international literature on medicine and health care-related topics from 1966 to present;

HealthSTAR: includes all published literature in the areas of health administration, planning, facilities and personnel administration from 1975 to present;

CINAHL: a multidisciplinary database including published literature in the area of nursing, allied health, biomedical, and consumer health literature from 1982 to present

SOCIOFILE: includes published journal articles, books, and conference papers in sociology and related social science disciplines

These databases were searched using the following key terms: “waiting lists”, “waiting times”, in conjunction with “accessibility” and “non-price rationing”.

A thorough search of published books was conducted using the online catalogue system at both the University of British Columbia and the University of Ottawa. In addition, book references were sought through the Internet at “www.amazon.com”, one of the largest listings of available books.

Unpublished Literature

The identification of unpublished literature presented more of a challenge and therefore required several approaches. First, key Canadian stakeholder groups including health care organizations, research institutes and government ministries were identified through contacts known to the investigators (Barer and Sheps) and the *Directory of Associations in Canada* and the *Canadian Research Centres Directory*. Key international research institutes with an interest in waiting lists were also identified. Second, a preliminary search of the web sites of these key groups was conducted via the Internet to identify sources of information and contacts. Third, contact was made with each group via either e-mail or telephone for a formal request for information. Finally, an additional fugitive literature search was conducted through the library services at the Centre for Health Services and Policy Research, UBC.

1.2 Synthesis Strategy

The key objective of this work was to synthesize all relevant published and unpublished sources of information which contribute to a more comprehensive understanding of the nature of waiting lists and waiting times. As such, a broad range of studies and works was identified. The canvassed literature has employed a rich mix of methods to investigate various aspects of waiting lists and waiting times. It is very diverse in both purpose and methods. The information presented in this report has been organized around key questions which focus on the following aspects of waiting lists:

- ▶ conceptualizations of waiting lists;
- ▶ definition and measurement of waiting list size and waiting times (reliability and validity);
- ▶ characteristics of waiting lists and waiting times;
- ▶ factors affecting waiting lists and waiting times;

- ▶ effects of waiting lists on patients; and
- ▶ strategies adopted to address waiting lists

In most cases, a particular reference could be categorized under one of these organizing aspects, based on the primary purpose of the document. Within each section, relevant studies are described and critically reviewed where appropriate. The later applies primarily to empirical studies based on primary or secondary data analysis.

In the sections that follow, we address in turn each of the key aspects of waiting list sizes/times noted above. In each section, we critically review the relevant literature, identify information gaps, and attempt to draw conclusions and implications.

2.0 How are waiting lists conceptualized?

In Canada, as in other countries with publicly funded health care systems, waiting lists are often assumed to mean the same thing to all people at all times. For the most part, waiting lists are viewed as an indicator used to assess the state of the health care system. In the Canadian context, waiting lists are often characterized by the media, and others, as leading indicators of health-threatening access impediments to publicly funded health.

In common parlance, a “wait list” suggests more patients than what current capacity can service. In the stylized world of the neoclassical economist, such a situation would only, if ever, exist in the very short term, while markets were adjusting (indeed, in the extreme, markets also adjust instantaneously, so there would never be a wait list unless there was some market rigidity that needed to be removed). If the quantity demanded of the particular service exceeds the available supply of that service, one would expect prices to adjust (upward) in the short term. In the longer term, capacity could be expected to expand to the point where the marginal cost of producing an additional unit of that service is approximately equal to the price consumer/patients are prepared to pay for it. But of course this would require fully informed patients/consumers, costless and instantaneous information, and a variety of other fanciful notions that are somewhat removed from the real world of health care.

Nevertheless, some of the baggage and confusion from that highly simplified world can be found in the literature on wait lists and wait times. Paramount in that confusion is a widespread tendency to talk of patients' "demands", excess demands, and the like, without being clear about who is doing the demanding, what role effectiveness and efficiency information play in determining who is "demanding" what, a failure to distinguish "demands" from "capacity to benefit", and a tendency to oversimplify the purposes of wait lists. Below we attempt to ferret out some of the predominant conceptualizations of wait lists in the literature canvassed. This is an important exercise since many of these conceptualizations reflect general beliefs regarding the major causes of and solutions for wait lists. If, for example, one conceptualizes wait lists, from the outset, as indicators of excess patient demand, then it is not a long leap from finding evidence of wait lists to calls for user fees to 'dampen' such excess demand. Similarly, if wait lists are assumed at the outset to be indicators of inadequate capacity, then the empirical observation of wait lists would lead rather directly to calls for increased capacity.

In the following section, we outline the various conceptualizations and definitions of waiting lists as they appear in the published and unpublished literature.

2.1 Indicator of Unmet Need

Perhaps the earliest and most frequently cited definition of wait lists focusses on the notion of unmet patient need and/or demand for health care services. Early references indicate that wait lists were originally taken as a measure of unmet demands for health care services or more specifically as an indicator of the lack of correspondence between, for example, the need for admissions and availability of health care services (Williams, 1968; Kennedy, 1975; Mason, 1976). The notions of need and demand, and the issue of who defines need, were often blurred or simply not addressed. The notions of patient demand and need for health care services continue to be used in the literature on waiting lists and waiting times, often interchangeably. For example, recent references have described wait lists as an indicator of excess demand, that is, the result of a situation in which demand for health care services exceeds supply (Cullis & Jones, 1983; Frankel, 1991; Globberman, 1991(a); Mullen, 1994; Naylor et al., 1994).

Whether “demand” is used in the economic sense of consumers being able and willing to purchase services that are not available, and just why prices do not then simply adjust to “clear the market”, are issues often left unexamined because of the need/demand confusion. In most cases, what is being described are “demands” for care as expressed through clinician/agents, in situations where prices play no allocative role. Such “demand” measures are quite distinct from the economist’s notion of consumer “demand”, and may also be different from objectively determined needs as defined by ‘capacity to benefit given existing clinical knowledge and technology’. Issues of cost-effectiveness of the interventions for which the queues exist are rarely addressed.

2.2 Indicator of Inadequate Resources

Another commonly held, but frequently disputed, definition of wait lists is that of an indicator of the inadequacy of resources within the health care system (Sanderson, 1982; Goldacre et al, 1987; Baume, 1995). Acceptance of this view leads inevitably to the suggestion that wait lists for surgical procedures can be eliminated by an increase in funding or resources (i.e. health care providers). The existence of such a simple relationship between wait list size and level of resources has been and continues to be disputed in the literature. Yates (1987) addressed this issue in his analysis of the variation in funding and wait list size among health regions in the UK. Variations in funding did in fact exist among regions since some regions offer a broader range of services than others as well as the fact that some regions accepted referrals across boundary lines. According to Yates, however, variations in funding did not explain variations in wait lists among the regions and therefore, an increase in resources does not represent the best solution to the wait list problem (Yates, 1987). Similarly, Frankel (1989) argues that wait lists should not be used as a measure of inadequate resources in the health care system but rather as an indicator of the need to better allocate resources.

2.3 Indicator of Misallocated Resources

The conceptualization of wait lists as an indicator of misallocation of resources within the health care system is further developed in the notion that wait lists reflect both physician and patient perceptions of disease. According to some, wait lists are not a universal problem but are restricted to a few surgical procedures. Those procedures with long wait lists represent

conditions that are not a priority for physicians, not of interest to the general public and/or not requiring urgent care. Wait lists, therefore, can be viewed as a vehicle through which the health profession and the public can prioritize health care services and allocate scarce resources to areas with offering the greatest potential benefit. Consequently, wait lists will change only when the perceptions of the disease change among physicians and the public (Frankel, 1989).

2.4 Indicator of Access to Health Care

The subject of waiting lists has also been raised in the access to health care literature. In their theoretical framework on access to health care, Aday and Andersen define wait lists and wait times as characteristics of the health care system which may affect utilization and consumer satisfaction (Aday & Andersen, 1974, 1975). In subsequent work, wait time is categorized as an individual enabling characteristic and determinant of patient satisfaction (Andersen et al, 1983). Wait lists and wait times are also defined as non-economic, aspatial barriers or obstacles between potential and realized access to health care services in the access to health care literature (Aday, 1975; Salkever, 1976; Fielder, 1981; Daniels, 1982; Khan & Bhadwaj, 1994) as well as the waiting list literature (Coyte et al., 1994; Ho & Coyte, 1994).

2.5 Mechanism to Ration Resources

Wait lists are viewed by many as a mechanism by which to allocate health care services in the absence of price rationing mechanisms (Bloom & Fendrick, 1987; Jacobs & Hart, 1990; Globerman, 1991 (a); Naylor, 1991; Baker, 1994; Light, 1997). Wait lists, therefore, exist in universal health care systems in which price for services rendered is not an issue, that is, supply and demand/need for services is not responsive to price. Lindsay et al. (1984) argue that waiting lists persist as a rationing tool because there are no direct costs associated with waiting since patients, while on the list, are still free to do as they please (Lindsay et al., 1984). While this may be the case for some patients, those requiring treatment urgently who are forced to wait will likely incur some type of personal cost (i.e. pain, disability) (Cullis et al., 1986). Opponents of non-price rationing argue that there are serious inefficiencies associated with this approach including obscuring supply and demand conditions, dealing with the social costs of waiting for care and the possible development of illegal black markets for

services. Furthermore, in order to avoid long waits, patients may seek to jump the queue or turn to private markets for care (Globerman, 1991(a)). Advocates of universal, publicly funded health care systems, however, argue that wait lists represent a far more equitable means of allocating scarce resources than those offered through price rationing. Steps must be taken to ensure the efficient and effective use of wait lists as a rationing tool (Naylor, 1991; Cox, 1994; Naylor et al., 1995). Extensive rationing by waiting lists may not be necessary if large sources of waste are removed at the organizational and structural levels within publicly funded health care systems (Light, 1997).

Wait lists clearly represent different things for different people and different systems. Why is this important? Because the conceptualization of wait lists can affect, or restrict, the potential policy options considered; for example, if one views wait lists an indicator of inadequate resources, the policy solution is obvious. Similarly, if wait lists are viewed as indicators of excess patient demand, this might lead to a policy of increased prices.

Despite these differences, the literature clearly indicates some areas of agreement regarding the interpretation and use of wait lists. First, wait lists represent some form of mismatch between the demand for and supply of specific health care services. This situation has been presented from the demand side as either "unmet need" or "excess demand" or from the supply side as "inadequate resources" (Amoko, 1992). The choice of presentation often reflects the authors' views regarding possible solutions.

Second, many researchers and policy makers concur that wait lists are an inevitable and unavoidable part of any publicly funded health care system. As such, wait lists are viewed as the "cost" of policies which attempt to remove the financial barriers from access to health care services. Opponents of universal, publicly funded health care systems have argued that this is an inefficient and potentially dangerous solution to a problem better resolved by market forces (Globerman, 1991; Sullivan, 1991; Rich, 1992). Supporters of universal systems, however, argue that wait lists are clearly a better alternative than price rationing mechanisms since they represent a fairer approach to the problem of constrained resources which does not discriminate based on income (Katz et al., 1991; Naylor et al., 1993; Ho et al., 1994; Naylor

et al., 1995). It is imperative, however, that wait lists be accurately measured, monitored and managed and that the experience of patients on lists also be actively monitored (Naylor, 1991).

Furthermore, the existence of wait lists per se does not necessarily represent a major fault with a health care system. Some argue that wait lists are essential to ensure the efficient use of constrained resources and to operate a system with no wait lists would require that capital and human resources would remain idle during periods of less demand (Yates, 1987). Excessive wait times for certain surgical procedures, however, clearly indicate a problem which must be addressed at the system level. Consequently, various researchers and policy-makers have concluded over the years that the focus must be placed on patient wait times for surgical procedures in addition to wait list size (Jones & McCarthy, 1978; Cullis & Jones, 1985; Yates, 1987; Frankel, 1989; Naylor, 1991). Wait list size is not an important issue for patients seeking surgical care (Mordue & Kirkup, 1989). Frankel (1989) argues that short wait times are perfectly acceptable since they are required to ensure the most efficient use of resources; long wait times, however, represent possible clinical problems for patients and organizational problems for the system as a whole. As such, the issue should not be why people are waiting but rather why people are waiting so long for certain surgical procedures (Frankel, 1989).

Finally, there appears to be general agreement among those who have studied the wait list situation regarding the need to ensure that policy solutions are based on reliable and valid data and sound empirical evidence regarding the nature of waiting lists and the factors which affect both wait list size and wait times (Williams, 1968; Jones & McCarthy, 1978; Cottrell, 1980; Weaver, 1981; Davidge et al., 1987; Jennett, 1987; Lee et al, 1987; Yates, 1987; Amoko, 1992 (a)(b); Naylor et al., 1994).

3.0 How are waiting list size and waiting times defined and are the data valid and reliable?

Since the early 1980's, numerous reports have been produced which provide information regarding the status of waiting lists and waiting times for selected procedures. There have also been numerous studies which focus on the basic characteristics of waiting lists and the

factors that affect them. The latter are conducted primarily to gain a more comprehensive understanding of the nature of waiting lists and waiting times. All these reports and studies are based on a range of data sources including survey data, hospital data, central registry data and administrative data.

With this surge in research activities, has come some concern regarding the quality of waiting list data (Deitch, 1981; Davidge, 1987; Yates, 1987; Amoko, 1992). The concerns focus specifically on the validity or meaning of the measures used (e.g. wait list size, waiting times) and the reliability or consistency with which they are used. In this section we review the studies which focus on assessing the reliability and/or validity of various types of wait list data. The review begins with a brief discussion of the basic principles and methods of validity and reliability assessments. This provides some basic criteria against which to critically assess this literature.

3.1 Criteria for Review: The Principles of Validity and Reliability

Data quality is most often assessed by examining the validity and reliability of the measures used to collect the data. Validity is concerned with the extent to which an indicator measures what it purports to measure, that is, with the meaning or construct of the particular measure. Construct validity is concerned with the extent to which the indicator reflects the theoretical concepts underpinning the phenomenon. There are various measures used to assess the validity of indicators or measures. The methods include comparing the measure to actual outcomes or to alternative validated measures; for example, correlation analysis can be used to assess the level of agreement. These methods seek to ensure that the measure or indicator reflects the various dimensions of the concept and conforms to theoretical explanations (Carmines & Zeller, 1979; Last 1988).

Reliability is concerned with the extent to which any measuring procedure yields the same results on repeated trials and is therefore, concerned with the degree of consistency and generalizability. While some degree of error is expected due to chance, a variable should demonstrate some degree of consistency in repeated measures (Carmines and Zellers, 1979). The methods used to assess reliability often depend on the type of data. With the increasing

use of administrative data in health related research, methods have been developed to assess the validity and reliability of such data. These are of particular interest since the majority of validity and reliability studies on waiting list data focus on the use of administrative data sources. The quality of such data may be threatened by coding errors, incompleteness, missing data, and/or duplication of records (Roos et al., 1979).

There are various manual and computer-based approaches used to assess the quality of administrative data which can be categorized as follows: (1) methods using patient records, (2) methods using 1 data base, and (3) methods using 2 data bases. The gold standard in assessing the quality of administrative data is the use of original patient records.

Administrative data records can be manually compared to information abstracted from the patient medical records. This is most often a very costly and time consuming process and not always possible when dealing with large administrative data bases containing several hundreds of thousands or millions of records. Furthermore, access to individual patient records is not easily granted and will usually require informal consent or other procedures that meet the test of ethical review (Roos et al., 1979).

Perhaps, the most common methods of data quality assessment involve comparison of two or more independent sources of computerized data. This method is deemed appropriate for any situation in which two data collection systems relate to the same event such as patient hospitalization, and are independent. The techniques of record linkage in which data files are linked at the individual patient level with the use of unique identifiers make it possible to compare information on the same event in two or more independent sources of administrative data. Patient information such as date of birth, gender and residence as well as information related to the procedure (i.e. type of procedure, date) can be compared and verified. This method can be used to assess the quality of diagnostic and comorbidity information in the administrative data (Romano et al., 1994; Hannan et al., 1997). Alternatively, two administrative data bases, such as hospital separation claims and physician claims, can be linked to confirm type of procedure, date of procedure and surgeon (Roos et al., 1989 (b); Roos et al., 1993). These computerized methodologies are appropriate for large data bases since they can produce results in a timely and efficient manner.

In what follows, we review studies which have assessed the validity and reliability of two primary measures associated with waiting list data: waiting times and waiting list size. In the remainder of this chapter, we draw on these concepts in evaluating the research addressed to the other key questions related to waiting lists and waiting times.

3.2 The Evidence: Waiting Time

Validity

Waiting times represent the most important measure associated with waiting lists. In theory, waiting times represent the time between when patients are placed on the waiting list (i.e. “date on”) and when they are taken off the list (i.e. “date off”). This seems like a reasonable assumption. Any issues regarding the validity of waiting times, therefore, clearly relate to the meaning and use of the key indicators, namely date on and date off. The latter appears to be less contentious since it presents the point at which patients are removed from the list due to receipt of treatment or other reasons (e.g. death, treatment elsewhere) which can often be confirmed by comparisons with other data sources.

The key issue arises from the apparently wide variation in the meaning and use of “date on” the waiting list. When are patients actually placed on the waiting list? Theoretically, the initiation of waiting time for a specific procedure or service should represent the point when both physician and patient agree that treatment is required. This has been represented in various ways in the literature through the use of specific markers. In their survey of CEOs, Jacobs and Hart (1990) defined waiting times as starting when the application for admission to hospital was made. They simply assumed that all hospitals involved in the survey employed the same working definition. In the absence of specific waiting time data, administrative physician claims and hospital separation data were used to proxy waiting time for a range of procedures in Nova Scotia. Date on the waiting list was defined to be the time of the last surgical consult prior to surgery since this was assumed to be the point when the decision for treatment was made (Nova Scotia, 1994). This method is problematic when there are multiple contacts with a surgeon prior to surgery. There was no analysis conducted to assess the validity of the measure.

There are various other definitions of date on the waiting list. The broadest definition offered to date is that of Bloom and Fendrick (1987) who in their attempt to measure total waiting time define the point at which a person seeks treatment, which in most cases begins with a visit to the general practitioner, as the relevant measure of “date on”. Alternatively, if there are several steps in a treatment process, the waiting time for a specific procedure may begin after the completion of the previous step; for example, Naylor et al. (1994) define the waiting time for CABG as starting at the time of angiography.

Placing patients on a waiting list may in fact be more complex than usually assumed. There are a range of patient and physician factors which may affect when patients are placed on a list. This further complicates the task of determining a useful definition of “date on”. In his discussion of waiting lists, Sanderson (1982) argues that the criteria for placing patients on the waiting list are not constant over time and place. He introduces the notions of admission and waiting-list thresholds. The admission threshold is the point at which patients require treatment and in an ideal world, they would be admitted at this point in time. However, patients are not constantly monitored nor are services always available when required. Hence, there is a waiting list threshold, defined as the point at which patients are judged suitable to be placed on the waiting list; that is, the condition has not deteriorated to a point requiring immediate admission to hospital (i.e. surpassing the admission threshold) but is expected to reach this point at some anticipated time in the future, preferably at the same time the patient reaches the top of the waiting list. The waiting list threshold may be different for different conditions and physicians, with low thresholds resulting in a long waiting list and vice versa (Sanderson, 1982).

Very few studies have focussed on determining the validity of particular measures of waiting times. As part of a broader study on knee replacement, Ho et al. (1994) investigated the validity of patient-reported waiting times. Retrospective measures of waiting times were obtained from patient surveys. One hundred and eighty-five patients were randomly selected from five hospitals in the Toronto area conducting at least 100 knee replacements during the study period (April 1, 1984- March 31, 1990). The results are based on 127 responses. Patients were asked to report waiting times for surgical consultations as well as for surgery.

The starting point for the latter was defined to be when both patient and surgeon decided that surgery was required. In order to assess the validity of waiting times for surgery, the patient reported times were compared to surgeon recorded waiting times. (The methods used to collect the latter are not reported). It was assumed that the patient-reported estimates of waiting times would be shorter than those recorded by the surgeons but the two measures would be correlated. The mean (median) waiting times were 15.4 (9.5) weeks (patient-reported) and 23.3 (17) weeks (physician-reported). The two measures were significantly correlated (Pearson's $r=0.38$, $p=0.001$) (Ho et al., 1994).

In the UK, Smith (1994) investigated the validity of inpatient waiting time as an indicator of the total time patients must wait for surgery. The author compared inpatient waiting time to the "post-referral" waiting time defined as the total time between referral from GP and time of admission. The "post-referral", or total waiting time, was comprised of three distinct waiting periods: (1) time between GP referral and first outpatient consultation (outpatient waiting time); (2) time between application for admission and placement on the inpatient waiting list (wait time between waiting lists); and (3) time between placement on the inpatient waiting list and admission (inpatient waiting time). Waiting time information was obtained from three different data sources: (1) outpatient records (outpatient waiting time); (2) inpatient waiting list data (wait time between waiting lists); and (3) inpatient records (inpatient waiting time). All three sources of data were linked at the individual patient level using personal health services identifiers. The study included all patients admitted to hospital for an operation in one of six specialties (orthopaedics, urology, gynaecology, ophthalmology, general surgery, otolaryngology) between June and August 1993 in three randomly selected Scottish hospitals ($n=3817$). The total number of cases for each specialty ranged from 275 for urology to 1454 for general surgery.

The average post-referral waiting time for all specialties was 110 days; on average, 58 days (52.7%) represented inpatient waiting time, 17 days represented the waiting time between waiting lists and 35 days represented outpatient waiting time. All values varied across specialties. The average post-referral waiting times ranged from 82 days for gynaecology and 136 days for urology. The average inpatient waiting times ranged from 42 days for

gynaecology to 86 days for otolaryngology. The proportion of total waiting time spent waiting for inpatient hospital care ranged from 40% for orthopaedics to 63.5% for otolaryngology. Additional analyses were conducted for cataract, knee replacement and hip replacement. On average, the inpatient waiting time represented only 53% (76 days) of the total post-referral waiting time for cataract and 48% (95 days) and 45% (74 days) of the total waiting time for knee and hip replacement respectively. The author concluded that inpatient waiting time represents approximately half of the total time patients wait for surgery (Smith, 1994).

Reliability

While there is very limited information regarding the meaning of wait time, there has been considerable discussion regarding the range and reliability of the methods used to measure waiting time. A variety of methods are currently being used and proposed in the literature and, not surprisingly, this leads to often disparate results. The following methods are identified in the literature (Cottrell, 1980; Weaver, 1981; Williams et al., 1985; Mordue, 1989):

- ▶ Cross-Sectional Method: also referred to as the cut-off method, reflects the waiting times of patients currently on the waiting list and is defined as the time between when patients are placed on the list and some arbitrary cut-off date (e.g. March 31). This method is commonly used with administrative databases to report the waiting times of patients on a list on a particular date.
- ▶ Retrospective Method: reflects the total waiting time experience of patients once they have received treatment. This method provides no information on the waiting times of patients currently awaiting surgery. Waiting times are commonly measured this way with survey data.
- ▶ Cohort Method: also referred to as the prospective method involves following patients from the time they are placed on the waiting list until they are removed; the waiting time is a measure of the time between these points. While this may result in the most valid and reliable measure of waiting time, it is considered the most costly and time consuming method and as such is not frequently used.

- **Expected Waiting Time:** represents the expected amount of time required to clear the waiting list and thus reflects the expected waiting time of the next patient to be placed on the waiting list. This measure is calculated as: No. of patients on the WL \div No. of admissions from WL per unit of time.

The cross-sectional and retrospective measures are perhaps the most commonly used methods. The Expected Time methods are intended to provide information regarding future expected waiting times versus existing waiting times. These measures have not actually been used in the literature to date.

The existence of multiple approaches to measuring average or median waiting times clearly raises the issue of the reliability and consistency of the measures. Don et al. (1987) investigated two different measures of waiting times used in Oxford, England. The first was a census measure provided biannually by the SBH 203 statistical returns which report the total number of patients waiting for surgery by specialty and district. Patients are classified into one of the following groups: urgent patients waiting one month or less, urgent patients waiting more than one month, non-urgent patients waiting one year or less and non-urgent patients waiting more than one year. Given the nature of census data, such records can easily be dominated by the longer waiting times. The second method was retrospective based on the use of inpatient admissions data provided through the Hospital Activity Analysis (HAA). The HAA provided information regarding the date of admission, source of the admission (i.e. emergency, waiting list) as well as the date when patients were placed on the waiting list; waiting times could be calculated for individual patients.

The study included a range of procedures, ENT, plastic surgery and gynaecology for five regions in the UK. For ENT, the proportion of patients waiting more than 12 months was higher as reported by the cross-sectional method compared with the retrospective method in three of five regions (Region 1: 32.2% vs 12.5%; Region 2: 35.8% vs 7.7%; Region 3: 21.9% vs 9.7%). Similar results were found for gynaecology with the largest discrepancies found in regions 4 (63.3% vs 11.7%) and 3 (42.3% vs 28%). The cross-sectional method is likely to identify a disproportionately high proportion of patients with longer waiting times, relative to the retrospective method (Don et al., 1987).

3.3 The Evidence: Waiting List Size

Validity

The meaning of waiting list size is rarely defined but rather assumed to be the number of patients awaiting treatment at a particular point in time. This measure is often presented as an aggregate value calculated at one of several levels including individual physicians, hospitals or regions. What is often not clear regarding the validity of wait list size is precisely who it represents. Does the measure represent all patients awaiting treatment? Does it include urgent or emergent cases or simply elective patients? Does it include day surgery or just inpatient care? Do measures aggregated at the hospital or regional level include all physicians?

A single study was identified which focusses in the validity of waiting list statistics, and it is again from the UK during the 1980's. Sykes (1986) assesses the effects of the exclusion criteria mandated by the Department of Health and Social Services (DHSS) when collecting waiting list information. The primary source of waiting list information in the UK at this time was quarterly SBH203 statistical returns which provide aggregated wait list information by length of wait to date and urgency classification (i.e. urgent vs non-urgent), by hospital and region. Those groups excluded from the official statistics include patients who wish to defer their surgery (including patients who have failed to accept an admission), day surgery, and patients who do not require surgery until a later date. Information for 1094 patients awaiting admission was obtained for 10 surgeons in an unnamed hospital.

The results of the analysis of the hospital waiting list data indicated that: 28.7% (n=314) declined an admission for medical or social reasons; 30% (n=325) were identified as possible day cases; and 20% (n=209) were identified as deferred cases. The proportion of cases in these categories varied by specialty. The number of excluded cases was adjusted for those patients who met more than one exclusion criterion. The official DHSS statistics indicated that only 608 patients were awaiting admission to hospital thus excluding 486 patients. The number of patients awaiting surgery in the hospital was 79.9% greater than that reported by the official statistics. The author concludes that the DHSS waiting lists statistics are misleading since they do not account for everyone awaiting surgery and they do not allow for proper comparisons across specialties (Sykes, 1986).

The validity of wait list size, as measured by administrative data, was assessed via comparisons with the actual measure, namely the hospital waiting list, a recognized method. The results indicate a significant under-representation of the actual measure; wait list size as reported by the official DHSS statistics did not include all patients awaiting surgery as reported by the hospital. The generalizability of the results is severely limited since the study is restricted to only one hospital. The results, however, were consistent across a range of procedures within the hospital.

Reliability

In most cases, waiting list size is assumed to represent accurately all patients who need and are prepared to undergo treatment. It is, therefore, often assumed to be a consistent or reliable measure. The majority of studies regarding wait list size focus on the reliability of the measure and most originate from the UK where administrative data on waiting lists has been available for some time.

Orthopaedic Care

Donaldson et al. (1984) reviewed waiting lists for orthopaedic in-patient services for eight orthopaedic surgeons in a large district hospital in Leicestershire Health Authority in England. The total list was comprised of 1,595 patients from the eight surgeons. The study was restricted to a review of patients on the waiting list for more than 1 year ($n=950$), representing approximately 60% of the total list. A preliminary review of patient records identified 193 patients (20%) who already had surgery but were not removed from the waiting lists. Questionnaires were administered to the remaining patients to determine whether or not they wished to remain on the waiting list and if not, why not. Respondents were asked to select one of the following: still want the operation, no longer wish operation, died, moved away, or already had the operation. Responses were obtained for approximately 88% of patients.

Of those patients remaining on the list ($n=757$), the majority of patients (48%) indicated that they still wanted to have the surgery; 65 (9%) indicated that they already had the operation; 70 (9%) had moved away from their listed address; and replies from relatives and searches of death records identified 34 (5%) patients who had died. 113 patients indicated that they no

longer wanted to have the surgery for a range of reasons including age (i.e. too old) and/or condition improved. The final results indicate that approximately 50% (n=475) of patients on the original wait list are inappropriately classified. There was a higher proportion of those still wanting the surgery among those under 45 years of age (43%) versus 75 and over (36%). There was a lower proportion of those no longer wanting the surgery among those on the list for 1 to 2 years (9%) versus more than 5 years (25%). There was a higher proportion of those no longer wishing to have surgery among those with minor operations (29%) versus intermediate (21%) or major (12%) operations (Donaldson et al., 1984).

In this study, administrative wait list data are compared to a gold standard, namely patient records. This first step resulted in the identification of 20% of cases that should not have been on the waiting list. The results of the survey may be conservative due to non-respondent bias since the proportion of patients still requiring and/or desiring surgery is expected to be lower among non-respondents than respondents. The most prominent limitation of the study is the generalizability of the results. Since the study focusses exclusively on orthopaedic in-patient services in one UK district hospital, the results may not be generalizable to other procedures. The intra-procedure generalizability is also limited since the study is restricted to patients waiting for surgery for more than 1 year and patients of only eight surgeons.

Hochuli (1988) also investigated the reliability of waiting list data for orthopaedic in-patient services in a single regional health authority in the UK. Patient information was obtained from the card index file used to compile names on the waiting list. Letters were sent to all patients appearing on an inpatient waiting list during a two month period (year not specified). Patients were asked whether they still wanted treatment and if not, why. Follow-up letters were sent and GPs were contacted to obtain information for non-respondents. There were 703 patients identified on the inpatient waiting list. The majority of patients (68%) indicated that they still wanted treatment; 17% had decided against any treatment; 5% of patients had already received treatment; and 10% did not respond to the letter. Among the latter group, 5% of patients had moved out of the district, 4% could not be traced and 1% had died. The author concluded that waiting lists do not represent a reliable measure of demand for health care services; they do, however, provide some insight regarding the organization of patient

services (Hochuli, 1988).

The methods used by Hochuli do not represent one of the recognized methods noted previously. Instead, the author relies on data from a patient survey. The results of the study, therefore, may be somewhat conservative due to non-response bias. In-patient waiting list information was provided by an out-patient clinic but there was no information provided regarding the number of hospitals or physicians involved in the study. Hence, it is impossible to comment on the intra-procedure generalizability of the results.

West and McKibben (1982) investigated the accuracy of a waiting list for orthopaedic outpatient appointments in three hospitals in the South Glamorgan Area Health Authority in the UK with orthopaedic outpatient clinics. The study included all patients on the waiting list as of March 31, 1978 (n=2256). A questionnaire was administered to all patients on the list to collect information on the current status of the patient as well as to determine if the patient wished to remain on the waiting list. After three mailings, 1702 (75%) patients responded to the survey with 285 patients indicating that they were no longer seeking care. Among the non-respondents, 88 patients reported by mail, or telephone that they were no longer seeking care and information was obtained from general practitioners for an additional 62 non-respondents indicating the patient was no longer seeking care. Overall, therefore, approximately 20% of patients indicated that they no longer sought an orthopaedic consultation. A follow-up survey was conducted 18 months later and was completed by 1434 patients (84% of those who completed first questionnaire) and 1049 patients (73%) indicated that they still had the same problem (West & McKibben, 1982). There is no information provided on the remaining respondents.

This reliability assessment is also not based on one of the standard methods described earlier but rather relies on the comparison of administrative data to information from patient surveys. As such, the results of the study may be conservative due to non-respondent bias. Furthermore, the generalizability of the results is limited. As noted in the previous study, the results cannot be generalized to other procedures since the study focusses exclusively on orthopaedic consultations. The intra-procedure generalizability, however, may be somewhat

greater since the study is based on the waiting lists of three hospitals. The generalizability of the results beyond the UK is unclear.

A similar study was conducted by Porter (1985) at the Royal Orthopaedic Hospital in Birmingham. Various processes had been introduced to promote the efficient use of hospital resources, including a systematic review of the waiting list via postal questionnaire, an out-patient review clinic and a pre-operative assessment clinic. Questionnaires were mailed to all patients waiting more than 3 years ($n=300$) to determine whether they wished to remain on the waiting list and if not, why. Overall, 73% of patients ($n=220$) responded to the survey. Fifty-five patients (18%) remained on the waiting list. Eighty-five patients (28%) requested to be removed and 80 patients (27%) were removed because they did not respond to the survey. Eighty patients (27%) requested a referral for an outpatient review. Patients waiting more than 1 to 3 years were immediately referred to the out-patient review clinic ($n=135$). A total of 215 patients were reviewed (i.e. included 80 patients requesting a referral) and of these, 162 patients (75%) were removed from the list and 53 remained on the waiting list. Patients were removed from the waiting list for various reasons including surgery not required, failure to attend, treated privately and listed on another NHS waiting list. Patients waiting less than one year were immediately sent to a pre-operative assessment clinic. A total of 130 patients attended the pre-operative clinic (i.e. included 55 patient requesting to remain on the waiting list and 53 patients remaining on the waiting list following the out-patient review). Among these, 78 patients (60%) were considered fit for surgery and 52 patients (40%) were removed. In the end, only 57 patients actually had surgery, 13 patients no longer required surgery and 5 had different operations. The author concluded that postal questionnaires, out-patient review clinic and pre-operative assessment clinic led to the removal of 55%, 75% and 40% of patients on the waiting list respectively (Porter, 1985).

A more recent study conducted by Elwyn et al. (1996) also focussed on the accuracy of waiting lists for orthopaedic outpatient care for one urban fund-holding general practice in Cardiff. The study is based on a systematic review of patient records for patients ($n=116$) who were awaiting orthopaedic consultations on April 1, 1994. The review was conducted by a general practitioner and a radiologist. Following a preliminary review of the waiting list,

approximately 28% (n=32) of patients were removed for various reasons: 14% were no longer registered with the practice, 7% were duplicate entries, 5% had been seen and 2% were excluded for other reasons. The medical records of the remaining patients (n=84) were reviewed to determine clinical priority and the need for further investigation. Among these patients, 14 were classified as high priority and were referred to other hospitals: 5 patients agreed to a referral; 6 patients declined the offer for referral; 2 patients did not show to discuss the issue and remained on the waiting list; and 1 patient underwent further investigation and was reassured and taken off the wait list. An additional 16 patients with low pain and disability scores were classified as low priority and referred to other hospitals. Twenty patients were identified as requiring further radiological investigations, 10 of whom underwent the procedure. Of these, 6 patients were given priority status and remained on the waiting list; 3 were removed from the waiting list; and 1 patient sought private care. Overall, therefore, the review resulted in a 50% reduction in the size of the waiting list. The authors conclude that while successful, the process was time consuming with substantial opportunity costs (Elwyn et al., 1996).

Elwyn et al. (1996) conducted their assessment of an orthopaedic waiting list using the gold standard (i.e. medical records) as well as expert clinical opinion. The results, therefore, would rank high on any validity rating. The generalizability of the results, however, is limited for several reasons. First, the study sample is small and therefore may not be representative of other patients attending orthopaedic clinics elsewhere in Cardiff or England. Second, the study is based on waiting list information for only one GP fundholding practice and there is no information regarding the representativeness of this practice.

Urology

The reliability of waiting lists for urology services was also considered potentially problematic, in the UK prompting various researchers to investigate the issue. Barham et al. (1993) reviewed a waiting list for transurethral prostatectomy in the Department of Urology in the Royal Devon and Exeter Hospital in Exeter England. The majority of patients were placed on the waiting list as a result of symptoms attributed to bladder outflow obstruction and evidence of an enlarged prostate gland. All patients on the waiting list were invited to undergo further

evaluation during a 1 week period, consisting of the completion of frequency and volume urine chart, interviews, and urine rate flow tests. There were 118 patients on the waiting list and 107 (91%) patients participated in the evaluation clinic. Among the non-participants (n=11), 4 patients had died, 4 patients refused reassessment and 3 patients had received the operation elsewhere. Following initial reassessment, 29 patients (27%) demonstrated evidence of severe obstruction and therefore, remained on the waiting list; 78 patients (73%) were interviewed and underwent further evaluation. Among the latter group, an additional 18 patients remained on the waiting list, 9 patients received out-patient treatment and 51 patients were discharged. Overall, 44% of patients evaluated (n=47) remained on the waiting list while the remaining patients (n=60) were treated in out-patient clinics or discharged. The authors concluded that routine evaluations of patients awaiting transurethral prostatectomy could substantially reduce waiting list size (Barham et al., 1993).

The authors used information from clinical evaluations to assess the reliability of a urological waiting list. This method is similar to that using medical records and therefore is expected to produce highly reliable results. The intra-procedure generalizability of the results, however, is limited since the study was based on the experiences of one hospital and a small sample of patients.

Schou et al. (1994) investigated the effectiveness of a standard evaluation programme for patients with benign prostatic hypertrophy (BPH) awaiting transurethral resection of the prostate (TURPS) conducted in part to reduce the length of the waiting list. To determine which patients were in fact candidates for TURPS, patients on the urology waiting list were asked to undergo a clinical evaluation consisting of a physical evaluation, symptom evaluation and routine blood sampling. Between May and June 1991, 132 patients were identified on a waiting list in the Copenhagen catchment area. A total of 117 patients agreed to the evaluation. The remaining 15 patients did not accept the invitation for various reasons; 4 patients had received TURP at another hospital; 9 patients felt their symptoms had improved and therefore did not require any further investigation; and 2 patients indicated that they did not have the time. Among those agreeing to the evaluation, 26 patients (22%) required no further evaluation and 91 patients (78%) demonstrated symptoms indicating further

investigation. Among the latter group, 11 patients were immediately referred for surgery and 80 patients underwent a full urodynamics study; the results of the study revealed obstructions for 61 patients indicating the need for surgery and no obstruction for 19 patients. Overall, a total of 72 patients were referred for surgical treatment but 11 patients refused surgery. Hence, 61 patients (52%) underwent surgery, 11 patients (9%) refused surgery and 45 patients (39%) were not deemed appropriate candidates for TURPS. Among the latter group, 17 patients were provided with continued care and 28 patients were discharged (Schou et al., 1994).

Once again, clinical evaluations were conducted to assess the reliability of a urological waiting list. As a result, 39% of patients were deemed inappropriate candidates for surgery and removed from the waiting list. While the methods are expected to produce highly reliable results, the generalizability of the study is limited due to the fact that it was based on a single hospital and a small sample size.

Various Procedures

A number of studies assessing the reliability of waiting list data have focussed on a broader range of surgical services. Lee et al. (1987) focussed on the degree of inflation in waiting lists for selected procedures in the Oxford region. The specialties include general surgery, ophthalmology, trauma and orthopaedic surgery, ENT, gynaecology and plastic surgery. These collectively represent 90% of patients on the waiting lists. Quarterly reports from the Department of Health's SBH 203 and Hospital Activity Analysis (HAA) for the time period between 1974 and 1983 were used. The study is based on the comparison of two sources of administrative data: (1) number of patients on the waiting list at the end of each quarter (SBH 203) and (2) admissions to hospital (HAA). The latter includes information regarding the source of the admission (i.e. waiting list) and therefore it is possible to construct a retrospective measure of waiting list size for those patients already admitted to hospital. This measure would not include those patients still waiting for care.

When compared over time, it is evident that the waiting list data as provided through the SBH 203 were consistently greater than the number calculated using the the HAA. There was a

positive correlation between the two data sets ($r=0.78$; $p<0.001$). The overall average discrepancy between the two sets of data from 1974 to 1983 was 38.7%. The authors note, however, that adjustments must be made to take into account missing data in the HAA data (10%) which would have resulted in cases that were included in the SBH 203 data but not in the former. The authors conclude, therefore, that approximately 28% of patients on waiting lists (after adjustments) are not eventually admitted to hospitals within the same region. They hypothesized that those patients on the waiting list who did not receive surgery would not have for various reasons including condition improved, treatment received outside the region, treatment received privately, treatment received on emergency basis, simultaneous listing on multiple waiting lists, patient moved, or patient died (Lee et al, 1987).

In this study reliability was assessed using two administrative data sets. The analysis was conducted at the aggregate level rather than the individual patient level as is recommended. It is not clear whether this method produces results that are as valid as those conducted with linked data sets. The approach may in fact lead to inflated estimates of inaccuracies. For example, the aggregate method does not allow for the identification of patients who were waiting for treatment at a particular hospital but ultimately received care privately or in another region. Such cases would appear in the SHB203 data but not in the HAA data and therefore, would be considered misclassified patients. These cases do not, however, reflect inaccuracies in wait list size since these patients actually did wait for treatment. The generalizability of the results is slightly better than other studies since it includes a range of hospitals. Results, however, were not presented by procedure; hence it is not evident whether all procedures were affected equally. This method assumes that waiting lists from a range of procedures are homogeneous and behave in a similar manner.

In New Zealand, an audit was conducted in the Dunedin hospital to assess the reliability of seven surgical waiting lists. Letters were mailed to all patients on the waiting list ($n=2216$) to determine whether they wished to remain on the waiting list and if not, why; 92% of patients responded to the survey. The majority of patients ($n=1679$; 76.6%) wished to remain on the lists; this varied across surgical departments from a high of 92.2% to a low of 60.3%. A total of 339 patients (15.3%) indicated they wished to be removed (Range: 4.7% to 25.5%).

Patients requesting removal from this list indicated a range of reasons, including that the surgery was no longer required, or the operation had been performed elsewhere. A total of 34 patients (1.5%) were removed because they had already had the operation or they represented duplicate names. The remaining patients (n=146; 6.6%) did not reply. This waiting list audit resulted in a decrease in waiting list size of 16%. The audit also revealed substantial variation between surgical departments regarding efficient administration of their respective waiting lists (Fraser, 1991).

The reliability assessment was conducted by comparing hospital waiting list data with patient survey data and therefore, may result in a conservative estimate of inappropriately placed patients. The generalizability of the results is limited due to the use of a single hospital site and although the analysis was presented for seven surgical departments, they were not identified.

The Standards Sub-Committee of the Victorian State Committee of the Royal Australasian College of Surgeons investigated the accuracy of waiting lists for surgery in seven Victorian public hospitals with the largest waiting lists across all surgical disciplines. The study is based on a point prevalence design with a stratified random sample of patients who were actively waiting for surgery in March 1987. A sample of 10% (n=2006) of patients with hospital unit record numbers were selected, stratified by surgical discipline. Only disciplines with more than 10 patients waiting and for which each waiting time period (i.e. <1, 1-3, 3-6, 6-12 and >12 months) was represented by at least two patients, were selected. Hospital records were used to collect information for all patients, including demographic data, insurance status, procedure, and date the patient was placed on the waiting list as well as any failed admission.

The results of the first phase indicated that approximately 20% (n=404) of patients had one or more failed admissions for various reasons, including unavailable hospital beds and patient refusal to attend; 20% of these patients (n=83) were inappropriately included on the waiting list. The second phase of the study involved a telephone interview with approximately 10% (n=206) of patients to determine if the patient's condition changed while awaiting surgery. Approximately 34% (n=71) of patients reported that the surgery was no longer required for

various reasons including patient's condition improved, surgery already performed at another hospital, patient had the surgery at the hospital but was not taken off the waiting list, or the patient died. Among those interviewed, 47% (n=97) of patients considered their condition changed while they were on the waiting list and 56 patients reported that their condition had deteriorated. These clinical changes were verified by physicians in 29 of these cases (Standards Sub-Committee of the Victorian State Committee, 1991).

Once again, this reliability assessment includes the use of medical records, as well as information from patient interviews. The study provides a broader perspective on the accuracy of waiting lists since it includes wait list information from a range of surgical disciplines and hospitals. While in theory this should improve the inter-procedure generalizability of the results, the study design is limiting. First, there is no information provided regarding the number and type of surgical disciplines included in the study nor any information regarding the specific sample size for each specialty. Second, the results of the study are aggregated across the different specialities; this implies again that waiting lists for different specialty groups are homogeneous and behave in a similar manner. Finally, the results of the patient interviews were based on a small sample and the results are expected to be conservative due to non-respondent bias.

3.4 Summary

While we find a limited number of studies which focus on the validity and reliability of waiting time and waiting list size, a reasonably consistent picture emerges from this literature. At the same time there are still considerable gaps in our understanding.

Waiting Times

Despite the limited amount of information, we can make some general observations about the validity and reliability of waiting times:

- ▶ There is very limited information regarding the validity of waiting time as a measure of time spent on the waiting list. This is due in part to the range of meanings ascribed to "date on" (ie. application of admission, last surgical

consultation, first contact with GP, date of pre-operative procedure) which marks the beginning of the waiting time.

- ▶ Waiting time is not measured consistently across time, specialty, procedure or place. There are a range of methods used (i.e. cross-sectional, retrospective, cohort, expected waiting time, expected waiting time to clear waiting list) which may result in different measures of waiting time. Evidence suggests that the cross-sectional method, in particular, is likely to over-estimate waiting times compared to the retrospective method.

There are a number of gaps in this literature bearing on the following issues:

- ▶ The construct validity of waiting times has not been fully explored. While the literature provides some insight on what waiting time (ie. “date on”) means, there may be a range of points in the course of treatment when a patient can be placed on a waiting list. These must be fully identified and explored in order to gain a more comprehensive understanding. In particular, prospective studies which follow patients from GP referral to surgery or review of medical records could be conducted to identify various points of entry to the list.
- ▶ Non-clinical factors which may affect when patients are placed on a waiting list have been virtually unexplored. They are likely to vary with the type of condition and anticipated procedure. Anecdotal evidence suggests that provider practices and patient choices may affect when they are placed on waiting lists. This information is necessary to test the assumption that patients are placed on the waiting list only when they require an intervention.

Waiting List Size

The majority of studies clearly focus on the reliability of waiting list size with most studies employing administrative data. The methods and results of the studies are summarized in Table 5.1. The following observations reflect the current state of knowledge:

- ▶ The evidence suggests that a considerable degree of inflation in many waiting list estimates. The majority of studies reviewed, found between 20% and 30% of patients on waiting lists inappropriately listed. A number of studies conducting full clinical evaluations found 50% of patients on the waiting list were there inappropriately. The generalizability of the results for each study is limited due to limited sample sizes and limited sites. The consistency of the magnitude is at least suggestive of results which may generalize, at least within the system environment from which they came (i.e. largely the UK).
- ▶ List length inflation occurs for various reasons including, patient death, treatment already received or treatment no longer required or desired.

While some progress has been made regarding empirical evidence on the reliability of waiting lists, issues still remain:

- ▶ The issue of overestimation of waiting list size should be further explored with more rigorous research designs. While some of the studies conducted to date are based on standard and acceptable reliability assessment methods (i.e. comparison to medical records) many are not (i.e. comparison to patient surveys). This area of inquiry should begin with further exploration of the validity or meaning of “date off”.
- ▶ The reliability of waiting lists may vary across specialties, and procedures. Waiting lists for more acute conditions such as cardiac care may be more reliable than lists used for more elective cases. It is important to determine which waiting lists are more or less reliable.
- ▶ The very limited number of studies from other countries other than the UK is a serious and significant gap in our understanding.

Table 5.1: Review of waiting list studies on reliability

Reference	Type of Study	Procedure	Source of Wait List Data	Study Sample			Methods	Results
				Hosp	MDs	Patients		
Donaldson et al (1984)	Cross-Sectional	Orthopaedic in-patient	Physicians	1	8	n=950* (n=757)**	Chart review* Patient Survey**	-193 patients had surgery (20%)* -282 patients no longer sought care (37%)*
Hochuli (1988)	Cross-Sectional	Orthopaedic in-patient	Out-Patient Clinic	n/a	n/a	n=703	Patient Survey	-5% of patients had been treated -17% of patients decided against treatment
West & McKibbin (1982)	Cross-Sectional	Orthopaedic out-patient	Hospitals	3	n/a	n=2256	Patient Survey	-435 patients no longer sought care (20%)
Porter (1985)	Cross-Sectional	Orthopaedic	Hospital	1	3	n=300* n=215** n=130***	Patient Survey* Out-patient review** Pre-op Clinic***	-165 patients removed (55%)* -162 patients removed (75%)** -52 patients removed (40%)*
Elwyn et al (1996)	Cross-Sectional	Orthopaedic	Hospital	1	n/a	n=116* (n=84)**	Chart review* Clinical review**	-32 patients removed (28%)* -26 patients referred or removed (31%)*
Barham et al. (1993)	Cross-Sectional	Urology	Hospital	1	n/a	n=107	ClinicalEvaluation Patient Interview	-60 patients removed or treated in out-patient (56%)
Schou et al. (1994)	Cross-Sectional	Urology	Hospital	1	n/a	n=117	ClinicalEvaluation	-45 patients removed (38%) -11 patients refused surgery (9%)
Lee et al (1987)	Retrospective	7 Surgical procedures	Health Region	n/a	n/a	-varied by time	Admin data	-28% inflation
Fraser (1991)	Cross-Sectional	7 Surgical procedures	Hospital	1	n/a	n=2216	Patient Survey	-339 patients requested removal (15.3%) -34 patients removed (1.5%)
Standards Sub-Comm (1991)	Cross-Sectional	All Surgical Specialties	Hospitals	7	n/a	n=2006* (n=206)**	Chart Review* Patient interviews**	-83 patients removed (4%)* -71 patients no longer sought care (34%)*

4.0 What are the general characteristics of waiting lists and waiting times?

Numerous studies have been conducted since the 1980's to determine the general characteristics of waiting lists and waiting times. These studies were conducted in an effort to gain a more comprehensive understanding of the nature of waiting lists and to address some key questions: who is waiting? for what procedure? is there variation in wait list size and waiting times and if so, at what level? The majority of studies focus on the experiences in the UK and in Canada.

4.1 Criteria for Review: Principles of Descriptive Studies

Most of the studies are descriptive in nature and based on cross-sectional or retrospective data. In general, the primary purpose of descriptive studies is to provide basic information regarding the distribution of a phenomenon across various groups and places as well as assess any changes in frequency over time. This information can then be used to generate testable hypotheses using more sophisticated designs and methods. Descriptive studies are most often conducted at the individual level within defined population groups (Henneckens and Buring, 1987). Given this general purpose, descriptive studies should: (1) be based on accurate data, (2) use appropriate statistical methods, (3) provide sufficient detail of the phenomenon, and (4) achieve a degree of generalizability. These basic criteria are considered in our critical review of the studies whose objectives were to uncover the general characteristics of waiting lists and waiting times.

4.2 The Evidence

The primary purpose of the study conducted by Davidge et al. (1987) was to review large waiting lists in order to gain a more comprehensive understanding of their basic characteristics. The authors believed that, at the time, the NHS was being forced to solve the problem without sufficient knowledge regarding the nature of waiting lists. The study, undertaken in 1986, was based on a review of 26 of the largest waiting lists in Wales and the West Midlands undertaken in 1986. Collectively, the waiting lists contained 31,224 patients waiting for surgery in one of the following specialties: general surgery, orthopaedics, ENT, gynaecology, and ophthalmology. For each patient, the data obtained from the waiting list

cards included demographic information, principal operation, other operations, location of residence, date placed on the waiting list, consultant and hospital. Usable information was obtained for 97% of cases.

The results indicated that 19% of patients waiting for inpatient care were 65 years of age or older; the results varied by specialty, ranging from 2% to 58% of patients 65 years and older awaiting ENT and ophthalmology respectively. Within each specialty, there was a small number of operations comprising a large proportion of the list; approximately 45% of patients were waiting for one of six procedures. These procedures represented the following proportion of cases in their respective specialties: varicose veins 27%, hernias 18%, total hip replacement 13%, arthroscopies 15%, tonsils and adenoids 44%, sterilisation 55% and cataracts 78%. While there was some variation across regions, a common pattern emerged regarding the most frequent procedures. Finally, the results indicated that over 45% of patients had been waiting for more than 1 year, with some patients waiting more than 5 years. This indicated perhaps a lack of routine reviews and the possibility of inflated lists. The study served to dispel some common myths regarding waiting lists, namely, that they are comprised primarily of elderly patients and of patients awaiting difficult and advanced types of surgery (Davidge et al., 1987).

This study provides some basic information regarding the composition of waiting lists and the characteristics of those awaiting treatment. No information is provided regarding the quality of the data. The results of the analysis clearly demonstrate the presence of variation in lists across and within procedures. The inter-procedure variation indicates that not all specialty waiting lists are the same. Information regarding the intra-procedure variation was limited to the ranges of proportions across the 26 waiting lists; in the case of wide ranges, it is not clear whether this is due to true variation or reflects simply the presence of outliers. Additional information is required to generate some hypotheses regarding the extent and nature of the variation. The study is based on a large sample size, thus contributing to the generalizability of the results. Only the largest waiting lists, however, were selected in a region known for large waiting lists. The generalizability of these results to other hospitals and regions with more moderate waiting lists is not clear.

Bishop (1990) examined waiting lists for urology in the UK based on national statistics provided by the Department of Health and Social Services for September 1987. The data revealed significant regional variation in the number of patients awaiting surgery. Wait list size ranged from just over 500 patients in Oxford to more than 5,550 in North East Thames. The pattern of aggregated waiting times was similar for a select number of regions (8 regions) with most patients waiting 2 months ranging from 80% in Mersey to approximately 56% in NW Thames. Likewise, the proportion of patients waiting 11 months varied from 50% in Mersey to less than 20% in the Northern region. The author contends that the variation may be due in part to the volume of out-patient treatment, surgeons' experience, adequate staffing in operating theatres and varying periods of post-operative in-patient admissions (Bishop, 1990).

The data clearly indicate the presence of regional variation in wait list size and waiting times for urological services. The data were not adjusted for population; hence, differences in wait list size could be due in part to different underlying populations across regions. The analysis of variation is restricted to the regional level; there is no information provided regarding variation at the hospital or physician level. Bishop's comments regarding the factors contributing to the variation, however, focus on hospital and physician characteristics. There is no information provided regarding possible regional factors contributing to the variation in waiting list size or waiting times.

Pope et al. (1991) conducted a study on five computerized waiting lists obtained for October 1988 from three general and two orthopaedic surgeons in a district hospital in the outskirts of London. The purpose of the study was to report waiting list size and times as well as to determine the variation in composition and waiting times among surgeons. Collectively, the waiting lists contained 1,283 patients who were actively waiting for care. The information available for each patient included, age and sex, consultant name, date of referral, procedure and urgency rating. The distribution of waiting times was highly skewed, with most patients waiting a few months and some waiting more than 5 years. In general surgery, 60% and 80% of patients waiting more than 1 year and 3 years respectively were waiting for varicose vein surgery or hernia repair. In orthopaedic surgery, 15% of patients waiting more than 1 year

were doing so for knee and hip replacements and 22.5% were waiting for surgery on other joints.

The results also indicate a high degree of inter-consultant variation in case mix, waiting list size and waiting times. For example, the waiting list size for the general surgeons A, B, and C were 298, 296 and 689 patients respectively and the corresponding average waiting times were 6, 11 and 10 months; hence, there appeared to be no relationship between wait list size and waiting times. Approximately 49% of patients waiting for surgeon B were waiting for hernia and varicose vein surgery compared to 34.2% for surgeon A and 39.7% for surgeon C. Similarly, the waiting list size and mean waiting times for the orthopaedic surgeons A and B were 238 and 265 patients and 15 and 8 months respectively; 31.5% of patients waiting for surgeon A were waiting for knee replacement compared to 1.5% for surgeon B. Finally, a significant association was found between urgency rating and waiting time using Chi-square analyses. While in general, waiting times were lower among more urgent cases, there were some anomalies; for example, several orthopaedic patients with an urgency score of 3 were less likely to have extended waits compared to patients with urgency scores of 2 representing more urgent cases (Pope et al., 1991).

The study focussed on two important characteristics of waiting lists, namely skewed waiting times and inter-consultant variation. The distribution of waiting times is important since it will affect the appropriateness of different statistical analyses. Despite the presence of skewness in the waiting time data, the authors chose to report means rather than medians, in doing so possibly conveying a misleading picture of wait times. No information is provided regarding data quality. It is possible that the skewness in waiting time may be due in part to inaccuracies within the data (e.g. patients not taken off the list). The authors also investigated the inter-consultant variation through comparisons of mean waiting times, wait list size and case mix. Given the distribution of the wait time data, it is unclear whether the difference in mean waiting time is due in part to the presence of individual outliers or whether it is simply a difference in case mix. The generalizability of the study is obviously limited, given the number of participating consultants.

Bloom and Fendrick (1987) investigated waiting times for medical care in Great Britain based on a variety of data collected between June and September 1984. Waiting time statistics for inpatient services were obtained from the Hospital In-patient Enquiry (HIPE), a 10% sample of inpatient discharges. Telephone interviews were conducted with hospital representatives and physicians to obtain information not included in the HIPE regarding waiting times for primary and specialty care for non-emergency, non-urgent ambulatory visits for new patients, existing patients and referred patients for specific diagnoses. The surveys were conducted among 43 randomly selected hospitals providing specialty care in the UK. To obtain information regarding waiting times for general practitioners, 33 community based physicians were randomly selected. The survey also included 10 full-time private practitioners in London, to collect some information on waiting times in the private sector.

The total waiting time was defined as the sum of all waits for non-emergency care for a range of specialties. The authors reported median waiting time for patients awaiting hospitalisation to be 14 weeks, with a sevenfold difference across specialties. The median waiting time ranged from 20 weeks for otolaryngology and orthopaedics to 4 to 5 weeks for general medicine, thoracic surgery and urology. Only 36 diagnoses were found for which patients had a median wait for admission of 9 weeks or longer. (The total number of diagnosis considered was not reported). The authors noted regional variations in waiting time but the intra-regional variation was larger than the variation between regions. The latter could not be explained by differences in population age and sex. Finally, the reported median waiting time for private care was only 3 days (Bloom & Fendrick, 1987).

Unlike previous studies, this one is based on a range of data sources required to calculate total waiting time from GP referral to treatment rather than simply waiting time for inpatient care. The authors combined two distinct types of data, namely administrative hospital data (HIPE) and survey data. The former represent retrospective measures of waiting times for inpatient care. The waiting times reported by hospitals and physicians in response to the survey reflect then current waiting times for patients (i.e. cross-sectional measure). The effect of combining these disparate sources of data is not readily apparent. Perhaps the survey could have included inpatient waiting times which could have been compared to the information obtained

from the HIPE to determine any discrepancies. The researchers did recognize the skewed nature of waiting time data and reported median times. They also reported some degree of inter- and intra regional variation, but did not provide any details regarding the extent or nature of the variation. Finally, the study was based on a random selection of hospitals and physicians and included a broad range of specialties, thus improving the generalizability of the results relative to other studies.

Several Canadian studies have examined the general characteristics of waiting list size and waiting times for a range of procedures. Globerman examined waiting lists and waiting times for selected procedures in British Columbia. Data were collected via a physician survey mailed to 606 randomly selected physicians representing 10 specialties based on mailing lists provided by the British Columbia Medical Association. The response rate was 24% (n=145) varying by specialty and region. Physicians were asked to report the total number of patients waiting for selected procedures and the average waiting times; reported average waiting times were weighted to reflect differences in patient volume. The total number of patients reported waiting was 7,840. Average waiting times ranged from 3.1 weeks (internal medicine) to 25.6 weeks (urology). Large standard deviations (not reported) indicated a high level of variability in both waiting list size and waiting times. The largest single group of patients (n=944) were waiting for cystoscopy and waited an average of 23.6 weeks. The next largest waiting list was for cataract, with 882 patients awaiting surgery with an average waiting time of 18.2 weeks. The author concluded that waiting lists should be monitored since there may be social costs associated with waiting which may vary by procedure (Globerman, 1991(b)).

The study was based on data collected via physician surveys. There was no consideration of the reliability or validity of the data. The response rate is low, thus adversely affecting the generalizability of the results. The results provide some evidence of variability in waiting list size and waiting time among the various procedures analyzed. The author did comment on the possibility of skewed waiting time data but still chose to report means rather than medians thus possibly overstating the actual waiting times.

Jacobs and Hart (1990) investigated waiting list times for selected procedures in Canada. The study was based on a survey of teaching hospitals conducted in 1989 to determine average waiting times for three procedures: hip replacement, coronary artery bypass and cholecystectomies. Questionnaires were mailed to the CEO of each teaching hospital ($n=57$); they were asked to report the average number of days from booking to admission; the response rate was approximately 80%. The distribution of the reported waiting times for all three procedures demonstrated a significant degree of skewness and variability. The standard deviation ($SD=104$) was greater than the mean (69 days) for cholecystectomies and was also very high for hip replacement ($SD=104$, mean=136) and heart surgery ($SD=84$, mean=108). Waiting times ranged from 0 days to 1 year for hip replacement and heart surgery; and from 7 days to 1 year for cholecystectomies. The average waiting times also varied by region, with the West demonstrating consistently higher average waiting times for all three procedures. The authors also noted considerable variation within regions; hip replacement in Quebec, for example, ranged from 30 to 300 days and from 0 to 315 days in Ontario. Respondents were also asked to indicate appropriate waiting times for each procedure and once again, there was variation in reported times. Heart surgery was the only procedure for which the mean reported waiting time (108 days) differed considerably from the mean reported appropriate wait time (54 days) (Jacobs & Hart, 1991).

The study represents one of the earliest attempts to collect waiting time data at the national level in Canada. There is no information provided regarding the state of waiting time data in each hospital nor the number of physicians represented. Based on the information presented, the distribution of waiting times as reported by the hospital CEOs is skewed; a more accurate reporting of waiting times, therefore, could have been achieved using medians or time interval frequencies. Furthermore, differences in actual reported waiting times and between actual and appropriate waiting times may be due to the effect of outliers.

Higginson et al. (1992) investigated waiting list size and waiting times for patients undergoing cardiac catheterization, percutaneous transluminal coronary angioplasty (PTCA), and open-heart surgery in Canada between April 1, 1988 and March 31, 1989. The study was based on data collected via a mailed survey to all directors of cardiac catheterization laboratories ($n=48$)

and the chiefs of all adult cardiovascular surgery programs (n=33). The response rate was 100% following two mailings and a telephone follow-up. Total population figures as of June 1, 1988 were used to calculate adjusted rates. Mean waiting times were weighted to reflect the differences in patient volume between centres. The results were presented by province with Nova Scotia, New Brunswick and PEI grouped since most surgeries were performed in Nova Scotia. The number of patients awaiting cardiac catheterization as of January 11 was 5012 (19 per 100,000); waiting list size ranged from 5.1 patients per 100,000 in Newfoundland to 30.9 patients per 100,000 in Quebec. The mean waiting time for Canada was 8.5 weeks ranging from 2.9 weeks in Newfoundland to 10.6 weeks in Nova Scotia. There were 952 patients (3.7 per 100,000) awaiting PTCA as of January 11, 1990; waiting list size ranged from 1.4 patients per 100,000 in BC to 6.2 patients per 100,000. The mean waiting time for PTCA ranged from 2.7 weeks in Saskatchewan to 15.4 weeks in Quebec and the national waiting time was 11.0 weeks. Finally, a total of 4495 (17.3 per 100,000) patients were awaiting elective open-heart surgery with the number varying from 6.7 per 100,000 in Saskatchewan to 25.1 per 100,000 in BC. The mean waiting time was 22.6 ranging from 7.9 weeks in Saskatchewan to 32.7 weeks in Quebec. The variability in waiting list size and waiting times reflected the differences in availability of facilities and specialists, attitudes and referral patterns across the provinces. They noted that regular collection of such data would inform resource requirements for cardiac surgery in Canada (Higginson et al., 1992).

This national cardiac study was repeated by Higginson et al. (1994) to determine waiting list size and waiting times for the same procedures in 1991 compared with figures in 1988 (Higginson et al., 1992). The number of patients awaiting cardiac catheterization decreased from 19 per 100,000 in 1988 to 15 per 100,000 in 1991 with no changes in mean waiting time; the rate of surgery increased during this time period from 236 per 100,000 to 256 per 100,000. Waiting lists for PTCA remained the same while waiting times decreased from 11 weeks to 9.2 weeks; the rate of surgery increased nationally from 39 per 100,000 population to 54 per 100,000. The rate of open heart surgery also increased from 63 per 100,000 in 1988 to 76 per 100,000 in 1991. Both waiting list size and waiting times decreased from 17 per 100,00 to 14 per 100,000 and from 22.6 weeks to 21.3 weeks respectively (Higginson et al., 1994).

The authors used the best available data on waiting lists for cardiac surgery. There is no information provided regarding the reliability or validity of the data. Participants were given the opportunity to review responses and make any additional corrections or adjustments. The analysis of variation was limited to the regional level and the data were adjusted for population size. Waiting times were reported as means; given the skewed nature of waiting time data, it is possible that the figures overstated the waiting times.

Naylor et al. (1993) investigated the management of coronary artery bypass surgery cases in Ontario prior to the implementation of formal queue management criteria and expansion of caseload capacity. This retrospective study was based on the chart reviews of 413 patients from four centres who underwent cardiac catheterization between October 1987 and April 1988. This led to the identification of 193 patients who were eligible for and proceeded to CABS. A 7 point urgency rating scale was applied to all cases, ranging from emergency cases (1) who were expected to be revascularized immediately to marked delay (7) where the expected waiting time was 3-6 months. Waiting times were defined to be the time between date of coronary angiography and surgery.

The mean waiting times varied between hospitals even after adjustments were made for urgency scores ($p < .0001$ with ANOVA). Average waiting times varied from 31.3 (S.E. 5) days at hospital B to 111 days (S.E. 37.7) for patients at hospital D. (Hospital D did not have onsite revascularization but patients were referred to either hospital A, B, or C). Even when the analysis was conducted without hospital D, the results were unchanged. Waiting times also differed between patients catheterized by cardiologists off-site versus those referred to on-site practitioners. A nested analysis of variance revealed that referral from hospital D was associated with longer waiting time ($p = .0046$); the results were even more significant when adjustments were made for urgency scores ($p < .0001$). The authors concluded that waiting lists are managed in part by clinical urgency but that explicit queue-forming criteria, audits, and mechanisms to redistribute patients are necessary to optimise the use of waiting lists to allocate resources (Naylor et al., 1993).

This retrospective study was conducted on highly reliable data abstracted from patient

records. Waiting times were clearly defined and measured consistently across hospital sites and patients. The distribution of the waiting times appeared to be skewed, making the use of means and parametric test (i.e. ANOVA) questionable. The study provides considerable detail regarding variations in waiting times. The generalizability of the results is limited to CABS and additional information is required to determine if the results are generalizable across other centres.

A similar finding was observed in BC for cardiac waiting lists. Katz et al. (1991) reviewed the waiting list situation for coronary artery surgery in BC during the late 1980's. A preliminary review of waiting list data in three BC hospitals revealed marked variation in waiting times across hospitals and physicians. The proportion of patients waiting more than four months ranged from approximately 50% to less than 10%. Waiting list size also varied among the 14 physicians performing the procedure. Approximately two thirds of the waiting list was accounted for by three physicians. Waiting list size ranged from less than 25 patients for one surgeon to over 150 patients for two other surgeons, all of whom were based at the same hospital. In another Vancouver hospital, 7 surgeons had waiting lists ranging from 10 to 50 patients while the eighth surgeon had approximately 125 patients waiting for cardiac care (Katz et al., 1991).

4.3 Summary

In general, these studies all attempt to identify key characteristics of waiting list size and waiting times. A range of data sources, methods and analyses were used. Hence, it is not possible to compare or aggregate results in any meaningful way. Despite these differences and limitations, however, the studies appear to agree on some general characteristics of waiting lists and waiting times. The majority of studies focus on the latter:

- ▶ The distributions of waiting times for a given procedure tend to be skewed. The distributions are most often a positive skew reflecting a small number of cases with exceedingly long waits. This may occur for a variety of reasons including actual long waits and/or some degree of unreliability in the data (e.g. cases not removed after treatment is received). Perhaps the first step when

presenting and analysing wait time data is to assess the degree of skewness in order to ensure the use of appropriate reporting statistics so that waiting times are not misrepresented. This problem can be addressed in several ways including use of non-parametric statistical analyses, the removal of outliers or transformation of waiting time data; the latter options will result in a more normal distribution. In many cases, waiting times are aggregated (e.g. < 3 months, 3-6 months, 6-12 months, >12 months) in order to address this problem. This often leads, however, to loss of information.

- ▶ Evidence suggests that there is often some degree of intra-procedure variation at various levels (i.e. physician, hospitals, regions). This is an important observation for two reasons. First, the presence of variation may render aggregation of waiting time data at the hospital or regional level invalid or at least highly misleading. Second, the presence of variation may be an indicator that patient, physician, hospital or regional factors are affecting waiting times. This information may be critical to the development of policies to address situations where wait times may be placing patients' health at risk.
- ▶ Evidence suggests that specialty waiting lists are not homogeneous as often assumed. The distribution of waiting times and degree of variation is not consistent across specialties and procedures. Aggregation of waiting list data across specialties and procedures, therefore, may be misleading; the results of such analyses may represent the reality for some waiting lists but not all. Specialty waiting lists need to be analysed individually in order to identify the specific characteristics of each type, since they may be affected by different determinants amenable to different policy options.

Information gaps regarding the basic characteristics of waiting lists:

- ▶ The majority of studies to date focus on selected specialties (i.e. orthopaedics, cardiac care, cataract). This is due in part to waiting list problems initially identified for selected procedures which have then motivated the focus of subsequent research. One almost never finds information regarding waiting lists for a range of other specialties and procedures.

5.0 What factors affect waiting list size and waiting times?

The variation in waiting list size and waiting times has been documented at various levels including regional, hospital and physician levels. The question now is: what are the specific factors which explain the variations in waiting list size and waiting times? There are a range of factors which have been hypothesized to affect waiting list size and waiting times. Returning to our discussion of the conceptualization of these variables, perhaps the most notable is funding. The common belief is that long waiting lists and lengthy waiting times are the result of inadequate funding.

A broad range of other factors are often implicated, however. These include patient characteristics (Turner et al., 1991) resource availability (e.g. number of physicians, rate of surgery), hospital characteristics (e.g. method of funding, admission rates, length of stay, emergency rates) (White, 1980; Buttery & Snaith, 1980; Harley, 1988; Katz et al., 1991; Ellis, 1991; Baker, 1994). While some of these may also represent various types of resources, their relationship to waiting lists and waiting times may be more complex than originally thought. The identification of these factors and information regarding the nature of their associations would allow for a more in depth understanding of waiting lists and waiting times. It would also provide some direction regarding policy development.

5.1 Criteria for Review: Principles of Association

Below we critically review those studies which focus on the identification of factors associated with wait list size and waiting times. An association is defined to exist when “the probability of an occurrence of an event or characteristics, or quantity of a variable, depends upon the occurrence of one or more other events, the presence of one or more other characteristics, or the quantity of one or more other variables” (Last, 1988, pg 7). There is a range of statistical methods available to assess the significance of an association including correlation measures, tests of central tendencies (e.g. ANOVA, Krustal-Wallis) and regression analyses. A statistical association can be said to exist if chance, bias and confounding are ruled out. The effects of chance are represented in p-values (e.g. $p < .05$) which are affected by sample size; hence, all else being equal, larger sample sizes result in smaller p-values indicating that

observed differences are less likely due to chance. Bias is usually introduced by the study design which results in some systematic differences occurring between groups; this could be a result of sample selection bias, data collection bias (interviewer bias, recall bias), ect. In such cases, the differences between groups or levels cannot be attributed to the variable of interest. Finally, confounding occurs when the association between two variables occurs as a result of other variables. To be considered a confounder, a variable must be related to both the outcome variable (dependent variable) and the variable of interest (independent variable). The effects of confounders can be controlled by including them in the analysis if they can be identified and data are available (Hennekens & Buring, 1987).

Significant associations, however, do not imply causation. Additional criteria must be met in order to conclude that an association is in fact causal. The criteria traditionally used in epidemiological studies which may be applicable to health services research include consistency, strength, temporality, and coherence (Hill, 1965; Hennekens & Buring, 1987). The principles of association and causality will be considered when critically reviewing the studies. In addition, given what is currently known about the reliability and validity of waiting list data and their general characteristics, issues of data quality, appropriate statistical methods and generalizability will also be considered.

5.2 The Evidence: Waiting List Size

Many of the earlier studies originate in the UK where waiting lists have been a concern since the inception of the NHS and governments have constantly strived to address the issue. Goldacre et al. (1987) conducted a study to investigate the relationship between changes in inpatient workload and the overall waiting list size. The authors hypothesized that there was an inverse relationship between admissions from the waiting list and waiting list size. The study was based on the use of data from the Hospital Activity Analysis which identifies the source of admissions (e.g. emergency, waiting list) as well as data on the number of patients on waiting lists, reported on a quarterly basis between January 1974 and December 1983. The procedures included in the study were general surgery, trauma, orthopaedic surgery, ENT surgery, gynaecology, ophthalmology and plastic surgery.

Overall, admissions from the waiting list represented approximately 56% of total admissions. Monthly admissions from waiting lists fluctuated widely. The monthly median was reported to be 5012 patients and ranged between 2155 and 6509 patients; the number of admissions from the waiting list showed a general increase between 1974 and 1979 followed by a slight decline thereafter. Admissions from other sources were fairly constant. Time series analyses were conducted to assess the effect of seasonal variation. Admissions from waiting lists tended to be below average in December and higher than average in November. Admissions from other sources were generally higher in the summer than winter. Over the ten year period, the median wait list size was 25,668 ranging from 20,388 to 31,239. There was no significant seasonal variation.

When the two trends were compared, there was a positive correlation between admissions from the waiting list and waiting list size ($r=0.35$, $df=38$, $p<.05$). The authors conducted several additional analyses to investigate the short-term association between admissions and waiting list size and the possibility that an increase in the length of the waiting list in one quarter might lead to an increase in admissions in the next quarter, but no such relationship was found. The authors concluded, therefore, that there was no inverse relationship between admissions from waiting lists and waiting list size as originally hypothesized. The authors offered several explanations for this seemingly counter-intuitive explanation, including inaccurate data, the use of waiting lists as a means to improve the efficiency of scheduling patients for surgery, and the increased likelihood of addressing previously unmet needs when waiting lists are reduced (Goldacre et al., 1987).

This retrospective study is based on 10 years of data and a large sample size, thus ruling out the possible effects of chance. The authors do acknowledge that the association identified could have resulted from inaccurate statistics, but provide no information regarding possible sources of inaccuracy; hence, bias may be present in the methods of data collection and/or reporting. The authors limited the analysis of additional variables to the effect of seasonal variation and industrial action (results not reported). Thus the possibility of confounding is not eliminated. Finally, the authors noted fluctuations in admissions from the waiting lists over time but not in waiting list size, thus indicating the possibility of a non-linear relationship.

There is no specific information provided regarding the correlation measures used to assess the association.

5.3 The Evidence: Waiting Times

Harley (1988) investigated the relationship between waiting times and a range of indicators produced nationally in the NHS, representing regional socio-economic status and resource provision, among others, for all health regions in England. Two measures of waiting times were used: (1) percentage of non-urgent cases waiting over one year, and (2) notional time to clear the waiting list (NWT). The latter is defined as: $(\text{Waiting list size} \times 365) / \text{Discharges and deaths from waiting list per year}$. The results of the analysis indicated wide variations in NWT and waiting list size between regions, with the NWT ranging from 0 to 812 days and proportion of patients waiting over one year ranging from 0% to 79% across regions. Simple linear correlations were calculated to determine the relationship between the waiting time variables and a range of independent variables measured at the regional level.

The author hypothesized that poorer regions may have less per capita capacity and therefore longer waiting times; there was no significant relationship between the dependent measures and socio-economic status of the health regions. The author also hypothesized that the provision of health care resources may affect waiting times (i.e. low levels of resources would be associated with longer waiting times). There was a slightly significant association between proportion of patients waiting >1 year and unit size (number of beds) ($r=.03$; $p<.05$) and number of out-patient clinics ($r=-.03$; $p<.05$) but neither variable was associated with NWT. There was an inverse association between throughput and NWT ($r=-.06$; $p<.01$) and proportion of patients waiting >1 year ($r=-.03$; $p<.01$) indicating that regions with lower through puts may have longer waiting times. The strongest statistical association was found to be between average length of stay and NWT ($r=.07$; $p<.01$) and proportion of patients waiting >1 year ($r=.06$; $p<.01$). There was no association between either dependent variable and number of senior doctors per catchment population, discharges and deaths per doctor, and proportion of day cases. The author recognized that while there are some statistically significant associations, they are relatively small and weak. The analysis was repeated for the 30 districts with the longest waiting lists and the 30 districts with the shortest waiting lists.

The author concluded that those with long waiting lists do not demonstrate any consistent characteristics that distinguish them from the rest. Additional multiple correlations were examined using both dependent variables and those independent variables showing the highest one-to-one correlation since the effects may be a result of multiple factors; the analyses did not significantly increase the strength of the association (Harley, 1988).

The analysis is based on data for all 14 regions in the UK, resulting in very large sample sizes. Relatively small associations were found to be statistically significant as a result of large sample sizes. The analysis was based on data collected through the HAA and so is reasonably assumed to be consistent across all regions, thus ruling out the effects of bias due to data collection methods. It was based primarily on simple linear correlations which are important to identify significant factors but do not permit the evaluation of possible confounders. The multiple regression analysis was conducted to assess the simultaneous effect of a group of independent variables but information on interactions which may identify possible confounders is not reported. Preliminary descriptive analyses indicated inter-regional variation in both measures of waiting times, suggesting a skewed distribution; the use of parametric tests, therefore, is questionable. Finally, unlike many other studies, the dependent variables were not direct representations of waiting times as measured in days or weeks; hence, the generalizability of these findings to waiting times more generally is not clear.

Waiting times have been hypothesized to be associated with 'demand' for surgery. As is commonly known, demand for health care services is affected by both patient and physician factors. Physician 'demand' may be affected by practice style or 'signatures' and willingness or unwillingness to operate may be associated with waiting list size and/or waiting times (Cullis and Jones, 1985; Frankel, 1989). Researchers in Finland attempted to address this issue by investigating the association between waiting list size and surgical rates. The authors compared rates of surgery for seven procedures (varicose veins, herniaorrhaphy, cholecystectomy, haemorrhoidectomy, operation on hallux valgus, cataract extraction, and hysterectomy) with data obtained from the 1987 Finnish Hospital Discharge Register. Waiting list size data were obtained from an inquiry made to Finnish hospitals in 1987. The surgery data were obtained for all hospitals while the waiting list data were obtained for most publicly

funded hospitals but not all hospitals reported waiting lists for all procedures. The number of surgical procedures and waiting list size were adjusted for population size of the hospital catchment area and were compared using product moment correlations. The results of the analysis indicated a significant positive association for herniorrhaphy ($r=0.31$; $p<.05$; $n=44$), operation on hallux valgus ($r=0.61$; $p<.001$; $n=26$) and hysterectomy ($r=0.42$; $p<.05$; $n=36$). The association was positive but not significant for all other procedures except for cataract, which revealed a non-significant inverse relationship. The remaining procedures did not demonstrate significant associations.

Hospitals were then grouped into low, medium and high rates of surgery. Krustal-Wallis analyses of variance were conducted to determine differences in waiting list size between these groups within each procedure. The only significant association was for operations on hallux valgus; the waiting list size per 10,000 was 3.3, 7.9 and 10.2 for hospitals with low, medium and high rates of surgery respectively. These stratified analyses clearly indicate that in most cases, the relationship between waiting list size and surgery rate is positive but not linear. In general, most associations were positive, although not all were significant. The authors recognized that this analysis did not demonstrate causality. There may be numerous other factors which affect waiting list size and surgical rates (e.g. population characteristics) that need to be assessed simultaneously (Norberg et al., 1994).

The analysis of the relationship between waiting list size and surgery rates was undertaken for a range of procedures at the hospital level. For only 3 of 7 procedures was the relationship significant, yet all but one demonstrated a positive association. The lack of statistical significance in the other procedures may be due to small sample size. Information regarding waiting list size was obtained from hospitals, but there is no information regarding the method of data collection used at individual hospitals to determine whether there was any systematic bias. The analysis was restricted to surgical rates only; no other variables were included. It is possible that specific policies at the hospital level affected both waiting list size and surgical rates (e.g. caps on procedures) thus confounding the association.

The association between waiting times and a range of patient and institutional factors was

examined by Coyte et al. (1994) for knee replacement surgery in the US and Canada. Data for the study were obtained through a stratified random sample of 1486 Medicare recipients in the US and 516 patients in Ontario hospitalised for knee replacement between 1985 and 1989. All those selected were surveyed by mail to determine waiting times for surgical consultations and surgery. The overall response rates were 80%; the rate of response to specific questions was 60% to 65%.

The results of the analysis indicate that the mean (median) waiting time for surgery was 3.2 (2) weeks for the US national sample (n=371) and 5.4 (4) weeks for the Ontario sample (n=325). Multiple regression analyses were conducted to determine the effects of a range of factors on waiting times. Institutional factors including number of knee replacements performed at the hospital, type of hospital and number of beds, were significant determinants of waiting times for surgery in Ontario but not in the US. Mean waiting time for surgery in teaching hospitals in Ontario was 16.3 weeks compared with 10.4 weeks in non-teaching hospitals. Income, education and gender were not significant factors in either country. Race was not a significant determinant in the US. Age was inversely related to waiting times and condition prior to surgery was related to waiting times in the US such that older people and those with worse knee conditions had shorter waiting times. In Ontario, condition of the knee prior to surgery was not related to waiting times. Patient location (urban vs rural) was not associated with waiting times in Ontario but rural patients in the US experienced average waits longer than those in urban areas. Collectively, these factors accounted for 20.5% of variation in waiting times for both samples (Coyte et al., 1994).

Like most studies, retrospective data were used but unlike previous studies, the data were collected via patient survey. The results for both groups, therefore, may reflect some recall bias. Multiple regression analyses were conducted to consider a range of factors that may affect waiting times but there is no discussion of which factors are indeed hypothesized to directly affect waiting time nor how they might be expected to affect waiting times. Finally, variable coefficients are not reported, thus it is difficult to assess the magnitude of the effect of each significant variable on waiting time.

A series of studies have investigated the factors associated with waiting times for specific cardiac procedures. Gaffney et al. (1995) investigated the clinical and non-clinical factors that influence waiting time from initial angiography to angioplasty. The retrospective study was based on a random sample of 106 patients from two Belfast catheterisation laboratories who were undergoing first angiography and proceeding to angioplasty in 1991. Data were obtained regarding patient characteristics (age, gender, location, occupation, marital status), lifestyle habits (smoking, body mass index), history of myocardial infarction, family history, comorbidity, and severity of angina, from medical notes. Logrank tests for univariate analyses were conducted to assess differences in waiting times for defined groups. Significant differences were found by age (Chi-Square: 8.15; $p < .017$) with median waiting times reported to be 7, 28 and 14 days for patients under 45, 45-64 and 65+ respectively. Significant differences were also found with respect to affluence of the patients' area of residence (Chi-square=13.96; $p < .007$) with median waiting times of 7 days for deprivation quintiles 1, 2 and 5 and 47 and 69 days for quintiles 3 and 4 respectively. The results clearly demonstrate the absence of a linear trend. A multivariate analysis was conducted using the Cox proportional hazards model to determine the most significant factors affecting waiting time while adjusting for covariates and confounding. The results of the analysis indicate that presence of severe angina and history of myocardial infarction were significant factors. Limited details were provided regarding the latter analysis (Gaffney et al., 1995).

This study was based on highly reliable data with clearly defined waiting times. The results of the analysis, however, are based on relatively small sample sizes which will have an effect on significance values. The researchers did attempt to conduct a multivariate analysis which considered a range of factors and possible interactions but insufficient information regarding the model renders the interpretation of the results difficult. Medians were used to represent waiting times. Generalizability of the results is limited given sample size and single location.

Similar studies were conducted in Canada by Naylor et al. (1995) for coronary artery bypass. Following the establishment of a central registry for cardiac surgery in Ontario, researchers conducted a study to examine the experiences of 8517 patients leaving the registry between October 1991 and July 1993. The retrospective study is based on patient data routinely

collected at each cardiac surgery centre by a nurse co-ordinator and subsequently sent to the central registry office. For each patient, information regarding waiting time (i.e. time from registration to surgery) and acuity score (i.e. defined by clinical characteristics) was available. The analysis was based on 8213 patients who underwent surgery. The distribution of waiting times was skewed, with a median waiting time of 17 days (IQR: (4-51)). Once controlled for clinical factors, waiting times varied by hospital ($p < .001$) from 8 to 48 days. A multivariate analysis was conducted to determine the most significant factors contributing to waiting times. The factors considered included age, gender, symptom status (CCS class), recent MI, anatomy (condition of vessels) and risk from non-invasive test results. The most significant factors associated with waiting times were symptom status ($p < .001$) and anatomy ($p < .001$) (Specific coefficient values were not provided). Patients with class IVC angina underwent surgery 3-4 days faster than patients with IVB; patients with IVA received treatment 10 days faster than patients with class I-III angina combined (Naylor et al., 1995).

This retrospective study was based on the data obtained from a single registry where waiting times are clearly defined and data are assumed to be collected in a consistent and reliable fashion reducing the chance of bias. Likewise, the sample is large, thus ruling out chance as a possible explanation for associations found. Efforts were made to consider a range of factors simultaneously hypothesized to affect waiting times. Limited information is provided regarding the magnitude and direction of the association of these factors with waiting times.

An earlier study conducted by Naylor et al. (1993) considered the association of patient preference for surgeons and waiting times. The study sample included all patients ($n=571$) referred to a central referral office in Toronto by cardiologists from hospitals without on-site revascularization, between Jan 3, 1989 and June 30, 1991. 496 patients were accepted for the study. Relevant demographic and clinical information was provided to the referral centre by the cardiologist. In 20% of the cases, a specific surgeon or interventional cardiologist was specified; the mean waiting time for patients who did not specify a preference was 22.73 days compared to 35.31 among patients who did specify a preference ($p = .002$ after adjustments made for acuity scores). The authors concluded that a request for a specific physician caused significant delays (Naylor et al., 1993).

Table 5.2: Review of studies investigating factors affecting waiting list size and waiting times

Reference	Proc	Unit of Analysis	Data	Methods	Dep Variable	Independent Variables				
						Patient	Physician	Hospital	Regional	Other
Goldacre (1987)	Various	Health Regions	Hospital Activity Analysis	Time Series	Wait list size					-admission from WL* -seasonal variation
Norberg (1994)	Various	Hospitals	-Hospital Discharge Registry -Hospital waiting list data	Correlations	Wait list size			-surgical rates* (for selected procedures)		
Harley (1988)	Various	Health Regions	n/a	Correlations	-% cases waiting > 1 year -NWT		-discharges and death per MD	- throughput* -LOS*	-SES -# of beds* -# out-patient clinics* -# of MDs	
Coyte et al (1994) Canadian	Knee Replacement	Patients (n=516)	Patient Survey	Multiple Regression	Waiting time	-age, gender, income, education, location -type of arthritis, - condition before knee surgery		-type of hospital* -# of beds* -volume of knee procedures*		

Gaffney (1995)	Angioplasty	Patients (n=106)	Medical Records	Univariate (Log Rank test) Multiple variable analyses (Cox Proportional Hazard)	Waiting time	-age* -gender -location, -occupation, -marital status -lifestyle habits -history* -comorbid -severity of angina*			-SES*	
Naylor et al (1993)	CABG	Patients (n=496)	Cardiac Registry	Univariate	Waiting time	-patient preference for MD*				
Naylor et al (1995)	CABG	Patients (n=8213)	Cardiac Registry	Multivariate Regression	Waiting time	-age, gender -symptom status* -recent MI -anatomy* -risk of invasive tests				

Notes * significant association

5.4 Summary

A number of studies have assessed the effects of various factors on waiting list size and waiting times (Table 5.2). The studies are based on a range of methods and conducted at various levels (e.g. patient, hospital, region) and are primarily concerned with determination of association rather than causation. The diversity in the methods makes it difficult to consolidate results in any meaningful way. Nevertheless, we offer the following observations:

- ▶ **Patient Factors:** various studies have considered a variety of patient characteristics (e.g. age, gender, education, location, patient preference) to determine whether they explain any variation in waiting times. The intent of such analyses has been to determine whether access is distributed on the basis of clinical need rather than patient characteristics such as socio-economic status. There is limited evidence that any of these factors affect waiting time. Patient clinical status, however, has been shown to affect waiting time among patients undergoing cardiac surgery; this is expected since waiting lists for such procedures are often more actively managed.
- ▶ **Hospital Factors:** a common assumption is that hospital factors such as available resources and throughput will affect waiting list size and waiting times such that more resources and greater throughput are associated with shorter waiting lists and shorter waiting times. Selected indicators such as throughput, length of stay, type of hospital and volume of surgery have been found to affect waiting time in a limited number of studies. There is very little information regarding the direction and magnitude of these associations. There is certainly no empirical base from which we could currently draw conclusions about relationships between capacity or throughput and waiting list size and waiting times.

The literature is clearly at a preliminary stage with respect to the identification of factors affecting waiting list size and waiting times. There are significant gaps in the literature:

- ▶ There is currently no general theoretical framework which attempts to outline a comprehensive range of factors which may affect waiting list size and waiting times. The development of a framework would serve both to identify the range of factors as well as to provide some information regarding the pathways through which they affect waiting list size and waiting times. The studies to date have been limited in scope due to the absence of such a framework and limited availability of data.

- ▶ As is evident in Table 5.2, there are gaps in information regarding a whole range of patient, physician, hospital and regional factors which may affect waiting times. For example, patient choice regarding choice of physician and time of surgery has long been hypothesized to adversely affect waiting time. Patients' waits may be lengthened if treatment is postponed due to work, family commitments, holidays or specialist preference; conversely, waiting time may be shortened if patient cancellations and non-attendances are reduced (Fishbacher et al., 1986; Houghton et al., 1989; Koppada et al., 1991; Wildner et al., 1991). Waiting times may also be adversely affected if treatment is cancelled or limited due to various physician and hospital factors (Keene, 1989; Baker, 1994; Hamilton, 1997). Conversely, patients' waiting times may be reduced with changes in models of care (e.g. day surgery) (Miles, 1988). The prevalence of these events and their effect on waiting times are important and not well understood. Prospective studies could be conducted to track patient activities and events while waiting for surgery.

- ▶ While traditional epidemiological methods tend to focus on the effects of a single factor, there is clearly a need to promote studies which focus on a broader range of factors simultaneously in multivariate analyses. Waiting lists and waiting times exist in a complex environment affected by various forces at the patient, physician and hospital level. As such, complex models are required to consider these effects simultaneously, as well as assess possible interactions. For example, the introduction of hospital global budgets has been hypothesized

to adversely affect waiting lists and waiting times, in part due to the need to limit the number of specific procedures; this practice could affect physician practice by limiting the number of procedures s/he can perform. An analysis which simply considers physician practice volume would not accurately reflect this reality.

- Studies need to be conducted with a focus on specific specialty waiting lists. There is some evidence to suggest that waiting lists are not homogeneous and may respond different specialties or procedures may respond to different factors differently. Study designs should be developed to ensure greater levels of generalizability.

6.0 How are patients affected by waiting lists?

A critical issue regarding waiting lists and waiting times is how they may affect patients. Patients are personally affected by waiting times in a range of ways from excessive disability to undue anxiety and stress due in part to a lack of information and communication with hospitals (Bishop, 1990; Martin, 1995). In most cases, the plight of patients is brought to the attention of policy-makers, health care providers and the public through media reports. Researchers have argued for years that it is critically important to research the effects of waiting on patients in an effort to both identify possible adverse outcomes as well as to identify ways to ease the burden and possibly reduce the burden of delay (Naylor et al., 1994). The following discussion presents a review of studies which focus on investigating patients experiences while awaiting surgery.

6.1 The Evidence: Patient Experiences

One of the earliest studies was conducted by Freeland et al. (1987). The purpose of the study was to assess morbidity among patients awaiting tonsil surgery in the Department of Otolaryngology of the Radcliffe Infirmary in Oxford, England. The prospective study tracked patients entering the waiting list between 1983 and 1985. Patient questionnaires were mailed to all patients within 2 weeks of placement on the waiting list and while patients were on the

pre-operative ward. There were 125 patients admitted to the waiting list during the study period: 83 patients were adults and 42 were children. The majority of patients exhibited symptoms of non-complicated recurrent tonsillitis including sore throats, fever, otalgia. The average waiting times were 12.9 months (range 2-28 months) for adult patients and 7.1 months (range 1-23 months) for children. Among the adult patients, 23% reported symptoms every 2-4 weeks (43% of children), 29% reported symptoms every 4-8 weeks (26% of children), 23% reported symptoms every 8-16 weeks (26% for children) and the remainder reported less frequent symptoms. For most patients, symptoms lasted 4 to 7 days. Among those adults waiting more than 12 months, 48% were having no more than one attack every 8 to 16 weeks indicating that less sick patients may have been waiting longer. Approximately 20% of children were removed from the list due to asymptomatic conditions, suggesting that some children "outgrow" their conditions if the delay is more than seven months. The authors concluded that long waiting times did not adversely affect patient morbidity, most likely because the sicker patients were treated earlier. They argue that a waiting period may in fact be beneficial since some patients were eventually removed due to lack of symptoms, therefore, avoiding unnecessary surgery (Freeland et al., 1987). Of course these results cannot be generalized beyond the particular condition in question, tonsilitis.

West et al. (1991) focussed on the experiences of patients awaiting general surgery in the UK. The purpose of the study was to assess the medical, physical, social and economic problems of patients waiting for surgery. The study population included all patients greater than 16 years of age listed as waiting for general surgery on January 1, 1987 at one of three hospitals in the largest health district in Wales (n=572). All participants were mailed a seven-page questionnaire designed to inquire about the nature of the illness, pain experience, disability and physical limitations, employment situation, social activity and mental wellbeing. Questionnaires were returned by 353 patients (60%). Interviews were also conducted to validate information obtained on the questionnaire, to expand on the questionnaire information and to seek information from non-respondents; interviews were obtained with 253 patients.

The results of the study were based on responses to the interview and to the questionnaire if there was no interview conducted. The majority of men were waiting for operations on hernia

(35%), varicose veins (16%), and conditions affecting the prostate (18%). The majority of women were waiting for varicose veins (38%), and gall bladder and gallstones (29%). The majority of respondents (80%) indicated that they had been waiting for more than 1 year and 75% reported that they noticed their condition more than two years prior. Pain was the primary problem associated with waiting for both men and women. The Nottingham Pain score was used to determine the level of pain experienced by patients waiting for surgery and this was compared to pain levels among a “normal” group of patients as represented by a Nottingham general practice population. The pain scores were consistently elevated for all ages groups among the waiting list patient population but were typical of pain levels associated with conditions such as vascular disease, fractures and chronically ill patients, conditions which were prevalent among the waiting list population. Average pain scores among the waiting list population were 2 (75+) to 15 (0-15) times higher than those among the GP population for men and from 0.7 (75+) to 8 (0-15) times higher for women. For men, the other frequently mentioned problems included immobility, restrictions at work, limited recreation and discomfort. For women, other frequently mentioned problems included immobility, dietary restrictions and cosmetic considerations. These concerns varied by condition; for example, patients with varicose veins tended to report pain, discomfort, immobility and cosmetic considerations, while patients with hernias reported problems with work, mobility and recreation. A greater proportion of those on wait lists reported problems with work, looking after home, social life, home life, sex life, interests and hobbies, and holidays compared with the Nottingham GP population (West et al., 1991).

A similar study was conducted by the UK College of Health among patients awaiting orthopaedic surgery. The College of Health is a national charity established in 1983 to help people make the most effective use of the NHS. The study was conducted in 1991 in the Worthing District Health Authority and was based on in-depth interviews with 50 patients on the lists of four consultants awaiting hip and knee replacement. All patients would have remained on the waiting list for more than two years by April 1992 if money from the Waiting Time Initiative Fund had not been made available. The Initiative was introduced in 1987 to eliminate all waits longer than two years (additional details are provided in the following sections). The availability of additional funds allowed for the admittance of 1175 long wait

elective surgery patients over and above the usual number admitted.

Fifty patients were interviewed in their homes prior to surgery and 33 of these patients were interviewed again following surgery. The interviews gathered information regarding the following issues: waiting time, private treatment, coping with pain, mobility, loss of dignity, effects on family life, being alone, financial effects, aids and adaptations, information from the hospital, holidays, admission, arrangements for discharge and patients' views of outcomes. While most patients had been waiting less than two years for surgery, they had been having problems much earlier. For some patients, the time between the initial request to their GP for a referral and treatment was five years. No patients interviewed were without pain and for some patients, the pain affected their quality of life more than anything else. Patients coped with the pain in a variety of ways, including "toughing it out", pain killers and alternative methods for those with conditions that did not permit the use of analgesics; not one patient was referred to a pain management clinic. Most patients reported limited mobility due to difficulties with driving or public transit. Most patients did not suffer financial consequences since they were retired, but they reported reduced quality of life since they could not pursue interests and hobbies and many had to cancel vacations. Patients also reported feeling like a burden for family members who had to care for them. Regarding hospital information, most patients simply wanted to know when they would be admitted and many were grateful to know they would be admitted even with short notice of admission. The author concluded that much work could be done to improve the situation of patients on waiting lists. In addition, the author suggests that national waiting list statistics should more accurately reflect total waiting time to surgery (Rigg, 1994).

Roy et al. (1996) investigated patients' experiences while awaiting orthopaedic surgery in Glasgow, England. At the time of the study, there were 280 patients on one surgeon's waiting list awaiting treatment. One hundred and twenty-three patients were invited to attend a research clinic; 21 patients indicated they no longer required surgery and 5 patients failed to attend. Data were collected from various sources including the activities of daily living assessment. Among those attending the clinic (n=97), 51 patients were classified as urgent and 46 were classified as non-urgent. The majority of patients were waiting for knee

replacements and hip replacements. The median waiting times were 3 months (range 1-30 months) for urgent patients and 23 months (range 1-78 months) for non-urgent cases. The majority of patients (n=90; 93%) reported pain; 44 patients reported significant pain at night and 29 reported constant pain. Most patients reported problems with mobility; 46 patients reported mobility problems indoors, 81 reported problems outdoors, and 75 reported problems with stairs. Thirty-eight patients reported problems with deformity. Overall, problems with pain, mobility and deformity were significantly more common in urgent patients ($p<0.05$). Patients also reported problems with various activities of daily living including shopping, pursuit of hobbies, visiting friends, housework, and picking objects off the floor. Support with some aspect of daily living was required by 60 patients and in most cases, help was provided by family and/or neighbours. Urgent and non-urgent patients differed only with respect to physical activity and depression in which the non-urgent group demonstrated a higher levels for both factors. The authors concluded that patients awaiting treatment must be reviewed and monitored for both clinical and functional status (Roy et al., 1996).

Most of the research regarding patient experiences focuses on cardiac surgery. One of the earliest studies was conducted by Mulgan and Logan (1990) in Wellington, New Zealand. The primary purpose of the study was to determine patient experiences while awaiting cardiac surgery. The study was based on questionnaires sent to patients (and their spouses) waiting for coronary artery bypass surgery on the Wellington Hospital waiting list who were not on the waiting list less than one month or more than 65 months or whose operation was not expected within the next week. Fifty-six patients (85%) and their spouses responded to the questionnaire providing information on work status, income loss, hospital re-admissions, communications with doctors and anxiety levels. The majority of respondents were male (91%), 32% had dependent children and 54% had spouses. The majority of patients (n=39) were in full-time work with normal workloads prior to developing cardiac symptoms. By the time of angiography and waiting list placement (median: 16 months), 34 patients were still employed and 5 patients had retired. Among those still working, 29% had taken time off work or reduced employment for cardiac-related symptoms, losing a total of 468 working days; for 18 patients, time off work was associated with a loss of income. Approximately 20% of all patients (n=11) reported financial hardships. Seventeen percent of patients

required readmission to hospital for an overall total of 52 days due to cardiac symptoms suffered while on the waiting list. Fifty-nine spouses participated in the study and 29 indicated that they had been involved in discussions with the surgeon. Less than half of spouses felt that their own health had suffered and level of anxiety increased. Current levels of anxiety were significantly altered compared with expected levels as determined by personality traits (43.3 vs 39.9; $p=.009$). The authors concluded that many of the costs associated with waiting for surgery are not immediately apparent and the cost effectiveness of coronary artery bypass surgery should include the costs associated with waiting for surgery (Mulgan et al., 1990).

Underwood et al. (1993) investigated anxiety, depression and social adjustments among patients awaiting coronary artery bypass grafting in a regional cardiothoracic centre in Leicester, England. Anxiety and depression were assessed using the Hospital Anxiety and Depression scale (HAD), a 14 item scale designed to screen physically ill patients; those scoring between 8 and 10 for either anxiety or depression are likely to be anxious or depressed and may require further assessment. Social functioning was assessed using a 9 point rating scale in which patients were asked to rate the extent to which various aspects of their lives (i.e. work, family relationships, social activities, leisure activities, and home management) were impaired (0=not at all; 8=severely impaired). Patients' clinical status was also assessed using the New York Heart Association (NYHA) classification of functional status of patients with heart disease. At the time of the study, there were 109 patients on two consultant waiting lists and each was sent a questionnaire. Sixty eight (62%) questionnaires were returned. Waiting time was defined as the time between when the patient was placed on the waiting list and the day the questionnaires were posted. The average waiting time was 6.4 months, ranging from 1.5 to 22.2 months. The results of the analysis indicated that most patients (72%; $n=49$) had borderline or non-significant scores on the HAD scale for anxiety; only 28% ($n=19$) of patients demonstrated clinically significant scores. There was a significant positive association between waiting time and anxiety scores (Spearman's $\rho=0.2$; $p<.05$). Forty-seven percent of patients ($n=32$) had clinically significant scores for depression on the HAD scale. Similarly, there was a significant positive association between waiting time and depression scores ($\rho=0.313$; $p<0.005$). The proportion of patients reporting definitive, considerable or severe impairment (Score ≥ 4) varied by task: 83% reported problems with

work, 75% had problems with social activities, 75% had problems with leisure activities, 65% had problems with home management, and 63% had problems with home relationships. There was a significant positive association between waiting time and impairment of work ($p=0.576$; $p<0.0001$), family relations ($p=0.486$ $p<0.001$), leisure activities ($p=0.414$; $p<0.001$), and social activities ($p=0.323$; $p<0.004$). There was no significant relationship found between clinical symptom status and waiting time. (Note: the majority of patients (96%) were in Class II or III demonstrating little variation in clinical status). The authors concluded that while strong conclusions could not be made from a study with such a small sample size, the results suggest some important associations that merit further investigation (Underwood et al., 1993).

A study conducted in Sweden compared symptom status and medication use among patients awaiting either coronary angiography or revascularization with a control group. All patients identified on three hospital waiting lists ($n=904$) as of September 1990 were mailed a questionnaire to collect data on symptom status and medication use. A total of 92% ($n=831$) of patients responded. The median age of patients was 63 (range 24-82) and 79% were male. The investigators randomly selected age and sex matched controls from the Swedish National Registry who were not awaiting revascularization. The median wait time for patients awaiting angiography was 8 months and 5 months for coronary artery bypass grafting and angioplasty. The majority of patients awaiting surgery, but few patients in the control group, were on anti-ischaemic medication. Fifty-three percent of patients awaiting surgery had daily attacks of chest pain compared with only 3% in the control group; 16% of patients reported no pain or less than 1 attack per week compared with 92% in the control group. On a scale of “no pain” (0) to “intolerable pain” (10), the median intensity of pain was reported to be 6.

Conditions such as anxiety, depression, restlessness, inability to act, difficulty relaxing, irritability and feeling stress were more common among patients than controls. There was no difference in age, frequency or severity of pain, stress reactions or physical exercise between patients with shorter (≤ 6 months) and longer (> 6 months) waiting times. But patients with longer waits had more nervous reactions (i.e. sleeplessness) ($p<0.01$), sleeping disorders ($p<0.01$), and tiredness in the morning ($p<0.05$). Patients with longer waits also used more sedatives (25% vs 18%; $p<0.05$) and smoked more frequently (23% vs 17%; $p<0.05$). The

authors concluded that longer waiting times were associated with more nervous symptoms but not with more pain (Bengston et al., 1994).

A similar study was conducted in Canada to explore the psychological and socioeconomic concerns of patients awaiting coronary artery bypass. The study setting was the Victoria General Hospital in Halifax, Nova Scotia, which provides all cardiac services for Nova Scotia and Prince Edward Island. The study was part of a larger study evaluating the hospital triage process. It was based on a sample of 423 patients referred for coronary artery bypass surgery between April 1992 and October 1992. The prospective study was based on interviews with 100 consecutive patients on the waiting list for non-emergency surgery selected from the original study sample. Interviews were conducted one to two days prior to surgery. The interviews were conducted using a structured questionnaire and explored the following factors: (1) communication, (2) anxiety, (3) satisfaction with support, and (4) economic hardships. Results of the survey were entered as categorical variables and analysed using Chi-square and Fisher's exact test when necessary.

The majority of patients (96%) deemed the explanation of the findings at catheterization and the justification for surgery satisfactory. Eighty-four percent of respondents indicated that waiting for surgery caused some degree of anxiety; 55% indicated moderate levels of anxiety compared with 9% who reported severe levels. Anxiety differed across age groups with younger patients expressing greater levels of anxiety; 76% of patients <60 years of age expressed at least moderate anxiety compared with 55% among patients 60 years of age and older. 16 patients expressed anger over the wait for surgery and all were upset that they had to wait at all for surgery. Fifteen patients, the majority of whom were under 60 years of age, identified economic hardship; blue collar workers were more affected (57%) than white collar workers (12%) ($p=.018$). Only 41% of patients indicated that they were satisfied with the level of hospital support; lack of proper communication was cited as the primary problem. The authors concluded that health care providers must be aware of the anxiety experienced by patients awaiting surgery. Furthermore, economic hardships are often experienced by younger patients, pointing to the possible need to include socio-economic variables, for given clinical acuity, when prioritising patients for surgery (Petrie et al., 1996).

The creation of the Cardiac Care Network (CCN) in Ontario sparked the establishment of the Cardiac Surgery Management System (CSMS) in the Central West region of Ontario which operated in conjunction with the CCN. The primary goals of the CSMS were to provide support, information and education to all patients awaiting cardiac care. Once patients are placed on a waiting list, they are contacted at various stages by a co-ordinator to provide support and information. A study conducted by Wright and Arthur (1996) investigated the following issues: the relationship between pre-operative anxiety and initiating contact with a co-ordinator; effect of discussion with the co-ordinator on anxiety levels; relationship between the provision of information and perceived knowledge regarding the surgery; and affect of the availability of a co-ordinator. Anxiety levels were measured on a five-point scale. This retrospective study was based on a questionnaire administered to a random sample of patients (n=150) who had undergone elective surgery in the previous year. The results are based on a response rate of 81%. The results of the study indicate a significant relationship between preoperative anxiety and initial contact with the CSMS; 70% of patients who reported that they discussed their anxiety with a coordinator reported feeling less anxious afterwards. The majority of patients also received educational material from the coordinator; 47% and 51% of patients reported that their level of understanding improved “somewhat” or “very much” respectively. The authors concluded, therefore, that preoperative anxiety does exist but can be managed through contact with CSMS co-ordinators (Wright and Arthur, 1996).

6.2 The Evidence: Patient Outcomes

While patients often feel the effects of waiting prior to surgery, claims are made periodically about waiting times also affecting patient outcomes. This is particularly true for cardiac surgery. Carrier et al. (1993) investigated the effects of waiting for elective open-heart surgery on patient outcomes at the Montreal Heart Institute. The retrospective study is based on data from 568 patients who had open-heart surgery between October 1991 and November 1992. Two hundred and six patients underwent elective procedures including coronary artery bypass grafting and valve replacement. Administrative data were used to collect the following information: age, sex, type of procedure, LOS, presence of pre-operative left ventricular dysfunction, previous cardiac surgery, waiting time and post-operative complications. All patients were retrospectively assessed for risk of death prior to surgery based on the Montreal

Heart Institute risk assessment classification. The average waiting time for elective cases was 2.8 months (median 2 months; range 1-17 months); only 20 patients waited more than 6 months. Nine patients died in hospital at or after elective surgery; 11% of elective patients were retrospectively assessed as having been at increased or high risk of death prior to surgery. When analysed by waiting times (≤ 2 months and >2 months), there were no significant differences between the two groups with respect to in-hospital death rate, incidence of post-operative complications, LOS in the ICU and total hospital LOS. Regression analyses found no association between waiting time and LOS in the ICU, total hospital LOS, death in hospital, post-operative complications or need for mechanical support. The authors concluded that the period of waiting prior to surgery had no effect on patient outcomes and that a policy of short waits prior to surgery was safe and acceptable if rapid access to care was not available (Carrier et al., 1993).

Koch et al. (1997) investigated the effects of waiting times on the success rate of elective percutaneous transluminal coronary angioplasty (PTCA). The study setting was the University Hospital in the Netherlands and is based on a study sample of 817 patients placed on the waiting list for PTCA between January 1990 and January 1992. The lesions were classified as type A, B or C based on the unmodified ACC/AHA criteria. Procedural success was defined as less than 50% residual stenosis without major cardiac events (i.e. death, coronary artery bypass, acute myocardial infarction or repeat angioplasty within 24 hours). Waiting time was defined as the time between the day the patient was accepted for angioplasty and the day of the procedure. Waiting times were divided into the following groups: less than 6 weeks (47.5%), 6 to 12 weeks (25%), and more than 12 weeks (27.5%). Demographic and clinical information was available for all patients. The analysis was conducted using means and t-tests for continuous variables and Chi-square for dichotomous variables.

The mean waiting time was 8.8 weeks with a range of 1 to 42 weeks. There were no deaths due to acute myocardial infarctions during the waiting time. The overall success rate was 87.9% (n=718). Waiting times were not associated with decreased success rates for lesions of Type A and B. In type C lesions, a decrease in primary success rate was associated with waiting times longer than 12 weeks (less than 12 weeks vs more than 12 weeks). Patients

were frequently examined by their cardiologist and prioritised based on the progression of the anginal symptoms; these clinical decisions, however, were not evaluated. The authors concluded that in the care of type C lesions, results may be improved by prioritising patients based on angiography, irrespective of clinical presentation (Koch et al., 1997).

6.3 The Evidence: Patient Acceptance of Waiting Times

Evidence suggests that while some patients may be adversely affected by waiting times, not all patients are dissatisfied with being on waiting lists. Recently, researchers have focussed on patients' acceptance of waiting times. In a study previously discussed, Ho et al. (1994) investigated patient acceptance of waiting times for consultation and surgery for knee replacement. The authors argue that patient acceptance of waiting times, particularly for chronic conditions, is essential to gain a balanced view of waiting times as an indicator of access to health care. Patients in Ontario who had undergone knee replacement surgery were asked through a mailed survey to report waiting times for initial surgical consultation (n=95) and surgery (n=96) as well as to comment on the level of acceptability of these waits (Surgical Consult: "acceptable" or "not acceptable"; Surgery: "too soon", "acceptable", "delayed too long"). Patients were also asked whether or not they were satisfied with the surgery. Overall, waiting times for consultation and surgery were acceptable to the vast majority of patients at 92.3% and 88.1% respectively. The median waiting times for surgical consultation for those who deemed them acceptable was 4 weeks compared to 7.5 weeks for those reporting unacceptable times. Similarly, median waiting time for surgery among those reporting acceptable waits was 8 weeks compared with 32 weeks among those reporting not acceptable. Patients' acceptance of waiting times was not associated with any measures of satisfaction (p-value varied between 0.48 and 0.97) nor with time elapsed since surgery (p=.34). The authors concluded that overall waiting times for surgical consultation and surgery were acceptable to most patients (Ho et al., 1994).

A similar study conducted by Dunn et al. (1997) investigated acceptable waiting times for cataract surgery and the factors associated with this phenomenon among patients in Manitoba, Denmark and Barcelona. The prospective study was based on data collected as part of the International Patient Outcomes Research Team (IPORT) from 550 patients recruited

consecutively from the practices of participating ophthalmologists. Patients were eligible for the study if they were seen by a participating physician, enlisted for a first eye cataract that did not involve a combined procedure, and were over the age of 50 and living in specified recruitment areas. The following information was collected from physicians and from telephone interviews with patients: anticipated waiting times (i.e. based on estimated waiting times as indicated by the ophthalmologist), evaluation of anticipated waiting times (“Shorter than you would like”, reasonable”, “longer”, and “much longer than you would like”), sociodemographic characteristics, health status, visual status (VF-14 Index, Cataract Symptom Score, overall trouble), and general attitudes about waiting times for unspecified surgery. Univariate analyses were conducted using chi-square, t-tests, ANOVA and univariate logistic regression; multivariate analysis was conducted using logistic regression with interaction terms.

The results of the univariate analysis indicate that study sites differed significantly with respect to all socio-demographic characteristics, health and visual status factors except gender and the Cataract Symptom Score. The median anticipated waiting times reported were 5 months in Manitoba and Denmark and 2 months in Barcelona. Only 28.9% of patients in Barcelona reported that the anticipated waiting time was longer or much longer than they would like compared to 43% in Manitoba and 56.8% in Denmark. The majority of patients reported that the maximum reasonable waiting time for non-emergency surgery was three months or less; however, almost one-quarter of the patients with anticipated waiting times greater than three months felt that these were reasonable. Logistic regression analysis was used to identify factors associated with the likelihood of patients perceiving anticipated waits to be “too long”. Significant factors include Cataract Symptom Score (OR=1.08; p=0.0259), self-reported trouble with vision (OR=1.75; p=0.0439), anticipated personal waiting times, and general attitude about a reasonable wait. The results were not consistent across sites with respect to the last two factors. Patients in Manitoba with anticipated waiting times of 3-6 months (OR=13.62) and more than 6 months (OR=13.03) were more likely to report waiting times were “too long” when compared to Manitoba patients waiting less than 3 months (reference group); patients waiting 3-6 months (OR=6.18) and more than 6 months in Denmark (OR=33.3) were likely to perceive the wait to be “too long” while only patients waiting more

than 6 months in Barcelona (OR=45.61) were likely to perceive the waiting time “too long” when compared to the reference group. None of the socio-demographic characteristics were found to be significant predictors of dissatisfaction with waiting times. The authors concluded that waiting lists may be better managed if waiting times are restricted to less than 6 months and possibly less than 3 months, and self-reported measures of visual acuity may be used to prioritise patients. There is no information provided regarding actual waiting times (Dunn et al., 1997).

Additional analyses conducted on the cataract data described above were used to explore patients’ willingness to pay for shorter wait times. The study was based on responses from 464 patients. There was limited support for higher taxes to reduce waiting times (12.3% in Barcelona; 23.9 in Denmark; 14.9% in Manitoba). There was also limited support for out-of-pocket payments to reduce waiting times. The authors noted an inverse relationship between willingness-to-pay and cost of surgery. Logistic regression was conducted to identify the factors associated with willingness-to-pay; more education, longer anticipated waiting times, poorer visual acuity in the better eye and a higher cataract symptom score were all associated with willingness to pay. Only 8 of the 464 patients paid for the surgery in a private clinic (Anderson et al., 1997).

The studies reviewed focus on a range of procedures including hip and knee replacement, cardiac surgery and cataract. Despite these differences, there are some similarities in design and common limitations. The majority of studies are based on retrospective accounts of patient experiences and therefore, may be affected by recall bias. Furthermore, the study data are often gathered through patient surveys and/or in-depth interviews. The cost of such methods often requires the use of smaller sample sizes. This may adversely affect the generalizability of the results.

6.4 Summary

There is no question that it is important to investigate the manner in which waiting for treatment affects patients. The studies conducted to date focus on a range of procedures including knee and hip replacement, cardiac care and cataract care.

Despite their differences, there appear to be some common findings:

- ▶ Patients awaiting surgery experience various physical effects. Patients awaiting elective procedures for chronic conditions are most likely to experience pain and some patients experience limited mobility and general discomfort.
- ▶ Patients awaiting care may also experience emotional strains such as increased levels of anxiety due to a range of factors including lack of information and uncertainty regarding the timeline for care.
- ▶ For those employed, waiting for care may result in lost productivity and economic hardships.
- ▶ Based on limited evidence, it appears that the burden of waiting may not be experienced by all patients to the same degree but vary depending on procedure, age, gender, and employment status.
- ▶ Despite the adverse effects of waiting for care, patients are not always dissatisfied with waiting.
- ▶ Despite some patients feeling waits are “too long”, very few would be prepared to see tax dollars go to reducing wait times, and fewer still seem prepared to pay out-of-pocket to reduce these waits.

Despite the increase in the number of studies investigating the burden of waiting lists, there remains much to do:

- ▶ It is not clear whether the full range of effects experienced by patients awaiting care have been identified and investigated for the full range of procedures. The burden of care can be categorized using the “seven Ds” which include death, disease, dysfunction, disability, dissatisfaction, distress and destitution (Naylor

et al., 1994). This information may in turn be used to develop or improve criteria used to determine patient priority status on waiting lists to ensure that those patients with the greatest need receive care first (Suttrop et al., 1992).

- ▶ There is very limited information regarding the effects of waiting on the families and caregivers of patients.
- ▶ There is limited generalizable evidence regarding the prevalence of physical, emotional, and economic burdens experienced by patients or the degree to which they affect patients. Prospective studies which follow patients from the start of their waiting period could be conducted to provide such information. Furthermore, standard measures should be identified to determine the extent to which patients experience these effects; it is difficult to compare study results when various measures and indicators are used to investigate these issues.
- ▶ There is no information available regarding the effects of waiting lists and waiting times on other groups such as providers, hospitals, and governments.

7.0 What strategies have been adopted to address waiting lists?

Waiting lists are not unique to the Canadian health care system. Indeed, they are found in most OECD (and presumably other) countries. They are particular issues within the publicly funded components of health care systems because they become the visible tip of the "rationing" iceberg for those interested in increasing (public or private) funding of health care. Furthermore, in situations where systems do not rely on willingness and ability to pay to ration access to resources, it is not surprising to find that available capacity and relative clinical need will end up being the variables that dictate how long patients wait for particular interventions.

There have been a variety of policies and strategies adopted to reduce waiting lists and waiting times both within and outside Canada. The policies range from local initiatives focussed on a single waiting list to national strategies aimed at reducing waiting times for a variety of services. The types of policies range from the development of local registries for specific services to national waiting time guarantees. In most cases, multiple policy approaches are adopted simultaneously to address different aspects of a waiting list situation. As such, the total efforts of a particular country or state must be considered to gain a more in depth understanding of the mechanisms through which these policies work to effect change. Such an understanding may also be assisted by some consideration of the various theoretical or conceptual perspectives on this issue. Accordingly, we begin this section with a brief discussion of those perspectives, and then move to a review of international efforts to address waiting lists.

If one has established both the existence of a wait list and the desirability of reducing its size or the median wait time, one has a choice of generic approaches. In the jargon of the economist, these choices can, for convenience, be described as "supply side" or "demand side" (bearing in mind our earlier discussion about the uses and mis-uses of the "demand" concept in this context). Supply side interventions usually involve adjustments to the availability of the key resource(s) seen to be the root cause of the wait list(s) in question. For example, cardiac wait lists in Canada have, in the past, been found to be related to the physical availability of operating suite space, the time management of operating suite space, and the availability of cardiac perfusionists (Katz et al., 1991).

There seems by now to be a general consensus in the literature that simply throwing additional funding at a system in the hope that a waiting list problem will disappear, is at best a very short-term band-aid with limited longer-term or enduring effects on waiting list size. First, if additional funds are provided without strict spending criteria, it is possible that they will be used for services other than those with long waiting lists. Frankel has noted, for example, that those procedures with long waiting lists are often not appealing to surgeons and thus additional funds would simply be spent on new, innovative procedures (Frankel, 1989). Second, even if funds are channelled into the creation of additional resources that would

address a wait list situation in the short term, in the long term, paradoxically, such additional resources can lead to increases in the number of patients being placed on waiting lists, leading to additional pressure for resources, and so on. It will come as no surprise to students of "financial incentives" that they are tricky little beasts (Morone, 1987; Giacomini et al., 1996). If having a long wait list leads successfully to the garnering of additional funds, it seems obvious what might happen if additional funds are thrown at the longest wait lists (Frost, 1980; Iversen, 1993).

This would suggest that any supply-side strategy must incorporate a careful assessment of the clinical requirements for additional resources, and these must be weighed carefully against other potential uses of the resources. In other words, supply strategies which take no account of the characteristics of the "demand" side, are unlikely to be effective. Nevertheless it is almost certainly true that where patients are required to pay significant out-of-pocket costs for hospital and physician care, waiting lists automatically get managed, in part, by price. This is unlikely to lead to resources being directed according to clinical capacity to benefit. More fruitful may be "demand side" approaches that recognize the critical role of the physician as patient agent, and therefore as the "consumer". Even here, however, it is critically important to bear in mind that this agency relationship may be "incomplete" (Evans, 1984), in that physicians usually have some personal economic stake in whether procedures are or are not undertaken, particularly if the physician receives fees tied to the procedures or services in question.

"Demand" side interventions could then include the development of management strategies or guidelines for physicians, intended to carefully select and prioritize patients, requirements for second, independent, opinions, and the like. But one need not necessarily presume that there is no role at all for patients in wait list management. Work out of Dartmouth Medical Centre, for example, has shown clearly that patients can be engaged in clinical decision-making and that, if they are provided with sufficient information about risks and benefits, they often make much more conservative decisions than their physicians. This could, of course, work to increase, or decrease, the length and median time of wait lists, which simply points again to the fact that list size and wait times can tell many stories (Flood et al., 1996).

With this preamble in mind, we turn to a review of some of the strategies and methods identified in the literature. The information is presented by country since, in most cases, multiple policies are adopted to address the issue and, as noted above, these need to be considered simultaneously.

7.1 England

England has perhaps the longest history of any publicly funded system with waiting lists. Waiting lists have been an issue since the inception of the National Health Service in 1948. Throughout the years, England has adopted several strategies to address waiting lists including the establishment of a national data system, targeted funding and waiting time guarantees. The following is an historical look at the policies adopted by the government in an effort to reduce waiting lists, as well as the participation of other groups to raise awareness of the issue.

7.1.1 National Waiting List Data

Department of Health

England has had a long-standing history in the collection of waiting list data at the national level. The first reported source of information was part of the Department of Health and Social Services statistical returns developed in the mid 1970s. Waiting list data for inpatient services were collected through two sources: (1) SH3 annual return (number of patients waiting as of December 31 by specialty) and (2) SBH 203 bi-monthly return (number of patients waiting by aggregated waiting time for urgent and non-urgent cases) (Cottrell, 1980; Williams et al., 1983). Data were collected from all hospitals in the UK for a range of specialties. These data, however, did not provide waiting times for individual patients. These data sources were heavily criticized since they excluded various types of patients such as outpatients, transfers and planned admissions. Therefore, they did not accurately represent the total number of patients waiting for care (Sykes, 1986).

Waiting list information could also be obtained retrospectively from the Hospital Activity Analysis (HAA). The HAA provided information on all inpatient admissions including date of admission, source of admission (e.g. waiting list, emergency, booked) and date placed on the

waiting list. Waiting time, therefore, could be calculated using the date on waiting list information and the date of admission. This information was not available from the SBH 203 data described above (Williams et al., 1983; Don et al., 1987).

In 1982, a Steering Group on Health Service Information, headed by E. Korner, deliberated on the collection and use of hospital information in the NHS. The recommendations of this group led, in part, to new policies and practices surrounding the collection of waiting list data. As of April 1, 1987, new waiting list data were collected, known as the “Korner KH07 returns: Demand for Elective Admission”. The returns include all patients waiting for admission to NHS hospitals including private patients and patients from overseas at specific points in time (June 30, September 30, December 31, March 31). The data variables were defined as follows:

- ▶ Patients waiting for admission:
Patients are classified as either having a date (i.e. offered admission) or no date. Patients who have been offered an admission date but declined are not counted until they have been offered a new date. Patients with planned admissions, or suspended patients (i.e. transplant) are not included
- ▶ Patient waiting time:
Waiting times are presented in aggregate format (<3 months, 3-5 months, 6-8 months, ..., >24 months). The data are cross-sectional in nature and waiting time is defined as the time between the “decide to admit date” for the provider and the date at the end of the applicable return. Waiting time for patients who declined or failed to arrive for an admission is calculated as the time between the original offer of admission and the end of the applicable return.
- ▶ Specialty: data are collected for 64 specialties.

The KH07 returns are submitted from all providers of hospital services in the NHS including Trusts, Special Health Authorities and District Health Authorities. Like other health data,

waiting list data represent one part of the minimum data sets that hospitals are required to collect for their own local administrative purposes. The Department of Health provides the software required for data collection. The data collected by hospitals are used by the Health Authorities to complete the data returns which are then submitted to the Department of Health on a quarterly basis.

The waiting list information is used for several different purposes including monitoring health authorities and Trusts, policy development, risk analysis, inpatient and out-patient modelling and to improve management of waiting lists. Waiting list information is reported regularly in publications such as the Department of Health *Statistical Bulletin* and the NHS Executive *Quarterly Review* (Dept of Health, 1997 a).

Efforts are currently underway to establish a similar database for first outpatient specialist consultations. The return is referred to as the “QMO8R” and is to be completed by each Health Authority reflecting the waiting times of their resident population. The following information has recently been collected on a quarterly basis for both medical and dental care:

- ▶ the total number of requests made for first time outpatient appointments;
- ▶ the waiting time of patients seen in that quarter between receipt of written referral from general practitioner to their first out-patient specialist consultation; and
- ▶ the number of patients at the end of the quarter that have yet to be seen for their first outpatient appointment and have been waiting 13 to 26 weeks or longer than 26 weeks following initial receipt of GP referral.

This development came about as a result of the waiting time guarantees outlined in the Patient Charter (to be discussed below). The Charter effectively guaranteed that 90% of patients can expect to get their first outpatient appointment within 13 weeks of receiving a written referral from their GP and all patients can expect to be seen within 26 weeks. Hence, data are required to monitor progress and inform policy development in this area. The first set of data are expected to be collected for 1997/98 (Dept of Health, 1997 b).

College of Health

During the early 1980s, the waiting list situation in the NHS gained increasing attention. This was due in part to the efforts of the College of Health, a non-profit organization established, in part, to provide patients with timely information regarding health matters and access to services within the NHS, as well as to provide managers and professionals in the NHS with information regarding patient needs. In 1984, the College produced the first in a series of annual "Guide to Hospital Waiting Lists" (1984-1991) reports since waiting list information collected by the Department of Health was not being made accessible. The Guides were based on aggregated data abstracted from the Korner returns for in-patient waiting lists as well as information from Welsh, Scottish and Irish sources. Waiting list and waiting time data were presented by region, hospital, and consultant for eight main surgical specialties (general surgery, trauma and orthopaedics, ENT, gynaecology, ophthalmology, oral surgery, plastic surgery and urology). These data were used primarily to provide waiting list information directly to patients and GPs in an effort to steer patients to providers with shorter waiting times (College of Health, 1990). The last Guide produced by the College of Health was in 1991 due to financial constraints.

In 1991, the College established the National Waiting List Helpline to provide waiting list information to patients experiencing problems. The Helpline provides the most up-to-date information on the waiting list size and waiting times for out-patient appointments and admissions for 9,000 consultants in 1,000 NHS acute care hospitals and for 88 different surgical and other procedures in 36 different specialties and sub-specialties. Data are obtained directly from the providers. Patients can call the Helpline and get up-to-date information regarding the waiting list status of their consultant or hospital and information regarding the best route for care including the identification of providers with shorter waits. In addition, the Helpline operators are very knowledgeable about the workings of the NHS and current government policies and so can provide more than just information on waiting list statistics. As of March 31, 1996, the Helpline had taken nearly 30,000 calls. This service is monitored by means of a postal questionnaire to patients using the system; results of the survey suggest that approximately two-thirds of callers were able to reduce their waiting times by either going to another hospital or by receiving treatment more quickly in their own hospital or through an

alternative consultant (College of Health, 1995, 1996 a)

Since the establishment of the waiting list Helpline, the College has been publishing a quarterly waiting list bulletin. These publications are based on the same data used for the Helpline, and report waiting list size and waiting times. The bulletin is provided to health authorities and hospitals as well as GP fundholders on subscription. The bulletin also includes information regarding the nature of the calls received from patients and their most pressing concerns. The March 1996 Bulletin, for example, indicates that patients were most concerned about cancelled operations and being forced to obtain care in the private sector (College of Health, 1996 b).

While the College of Health does not have any direct control over policy development related to waiting lists, it is their belief that they have served two main functions. First, the publication of the first Guide to Hospital Waiting Lists and subsequent publications have served to raise awareness of waiting lists and their effects at the national level. In fact, it has been argued that these efforts have served as the impetus for national policies aimed at reducing waiting lists (personal communication Marianne Rigg, Director). Second, the Helpline has aided individual patients in dealing with the burdens associated with waiting for care.

7.1.2. Waiting List Policies

Waiting List Initiative (1987)

By the late 1980s, waiting lists had gained significant political attention. The Waiting List Initiative represented one of the first national efforts to reduce waiting lists and waiting times. The primary purpose of the Initiative was to eliminate waits longer than two years. This was supplemented by a specific focus on joint replacement and cataract patients waiting longer than 18 months. Once the district and Regional Health Authorities agreed with the targets, they were challenged to eliminate all long waits (Dept of Health, 1998). District health authorities and/or hospitals were asked to propose strategies to reduce waiting lists and waiting times in their respective organizations. The proposals were then reviewed and if deemed appropriate, were funded based on need. The Initiative was supported by targeted

funds amounting to approximately £30 million a year nationally over the period 1987 to 1993. In 1990, funding was provided for 100 new consultant posts specifically created to reduce waiting times (Newton et al., 1995).

Waiting Time Guarantee (1992, 1995)

Waiting time targets were made more explicit with the introduction of *The Patient's Charter* in 1992. The primary purpose of the Charter was to set out the rights and standards that patients could expect from the NHS. The Charter guaranteed all patient admissions to hospital within two years and a guarantee of 18 months for joint replacement and cataract extraction. The Department of Health monitored waiting list returns for any breach of the contract.

In April 1995, the Charter was revised such that patients were guaranteed admission to hospital for all services within 18 months. In addition, patients could expect treatment for coronary artery bypass and related procedures within one year. Furthermore, patients could expect that operations would not be cancelled the day before scheduled or after admission to hospital. For the first time, the government introduced waiting time guarantees for first outpatient appointments with consultants once referred by a GP. Ninety percent of patients could be expected to be seen within 13 weeks and all patients could be expected to be seen within 26 weeks. However, waiting times are not guaranteed if patients choose to see a particular consultant (NHS, 1995).

7.1.3 Effects of Waiting List Policies

It is evident that waiting lists in the UK have been addressed on several fronts. Government efforts began with the collection of national data to monitor and compare waiting list size and waiting times across health regions, hospitals and specialties. This was followed by explicit policies to reduce long waits through the Waiting List Initiative and to establish waiting time guarantees through the Patient's Charter. The obvious question remains: has there been a reduction in waiting lists and/or waiting times? and if so, which policies are responsible and how?

There has been very little formal evaluation to date of the effects of the government policies regarding waiting lists. Several independent studies were conducted to evaluate the effects of individual Waiting List Initiatives conducted throughout the UK. The studies are based on the specific experiences of individual regions and/or hospitals. Despite the degree of variability regarding the study settings, proposals and methods, there appears to be some consistency regarding the effects of this type of policy.

Waiting list funds were used in the Worthington District Health Authority to undertake "Operation Cataract" in 1987. A suitable local hotel was selected to establish a temporary eye clinic. Patients were asked to report to the hotel the evening before surgery; they were given a medical examination and ophthalmological examination. Patients were examined following surgery and discharged three days post-operatively. The goal of the initiative was to treat 100 cases with priority given to cases who had been waiting the longest. Of the 217 patients who presented at the temporary clinic, 86 patients were no longer eligible. From the remaining patients, 100 were selected for surgery. The initiative was successful in reducing the ophthalmology waiting list in half and the reduction was maintained for nine months (Thomas et al., 1989).

Waiting list initiatives for ophthalmology were also conducted over a five week period in 1989 in one London hospital to reduce the waiting time for new referrals. An additional clinical assistant, nurse and secretarial time were obtained to provide extra services. At the start of the initiative, there were 317 new patients waiting for treatment and all were given an appointment; 81% of patients (n=258) attended the clinic. There were 327 diagnoses, most for cataract (25%). Overall, 57% of patients were discharged, 26% were scheduled for surgery or laser, 12% were referred for an out-patient review, 3% were given a specialist referral and 2% were registered blind. Following the out-patient initiative, waiting times decreased from 30 weeks to approximately 5 weeks. The authors concluded that the initiative was an effective way to reduce out-patient waiting list time (Lee et al., 1992).

Mills and Heaton (1991) investigated the effects of a Waiting List Initiative for ENT surgical waiting lists in a teaching hospital in Tayside, Scotland. Funds were obtained from the

Scottish Home and Health Department and were used to employ an anaesthetist on a sessional basis and additional nurses in order to increase the rate of surgery. The funds were also used to purchase a second air drill so that cases requiring the instrument could be treated simultaneously. The Initiative was conducted for a total of 18 months. Overall, 445 patients awaiting surgery were offered a date for surgery: 280 patients received an operation, 16 patients no longer required surgery, 39 patients were unfit for surgery and 116 patients cancelled. There were a total of 410 operations performed including minor nasal surgery, tonsillectomy and adenoidectomy. The authors concluded that, in the short term, the Waiting List Initiative did reduce waiting list size, however, the long term effects of the Initiative were not known (Mills et al., 1991).

Mackinnon et al. (1992) reported the effects of a Waiting List Initiative conducted to reduce waiting lists for orthopaedic surgery in a hospital in the South West Region of England. The hospital was awarded funding to remove 100 patients from the waiting list by running 25 outpatient clinics on Saturday mornings between June and December 1988. The funding was used to employ registrars in orthopaedics and anaesthesia for the sessions. Several patients seen in the pre-operative assessment were turned down for surgery due to medical problems, or simply because there was no clinical need for surgery. Overall, 119 patients had 123 procedures; 6 (5%) patients did not attend the assessment or surgery when called. The weekday non-attendance rate was 11%. The Initiative did not have any significant effect on total waiting list size or waiting times. Waiting list size more than doubled once the scheme stopped due to the number of patients placed on the list during this time. There was no change in the mean waiting time (6 months) nor in the distribution of waiting times from longer to shorter waits as was anticipated. The authors concluded that the weekend initiative was well received by patients and made good use of theatre space that otherwise would have remained idle (Mackinnon et al., 1992).

Parmar (1993) reported on the effects of a general surgery Waiting List Initiative conducted in a general hospital in North Staffordshire, England. Additional funding was obtained to employ a half time staff surgeon for six months commencing June 1991; in addition, hospital beds were allocated for the Initiative. Each week 20 patients awaiting treatment were sent a

questionnaire to collect medical history information and a patient information leaflet to explain their relevant procedures. The pre-operative questionnaire had 100% compliance. Those patients deemed ready for surgery were provided with an admission date within 4 weeks. Overall, 525 patients were assessed; 78 patients did not have surgery for various reasons including that they already had the operation, they did not want the operation, they did not need the operation, moved away, or failed to attend. A total of 447 patients had 566 operations, mostly for varicose veins (59%) and hernias (16%). Waiting list size decreased by 32% from 2254 patients at the start of the Initiative to 1529 patients by the end of November 1991. The author concluded that the Waiting List Initiative was successful in reducing waiting list size but that efforts must be directed toward prioritizing patients on the list (Parmar, 1993). Others cautioned against the use of such Initiatives for more complicated procedures such as hip and knee replacement since the use of extra sessions and less experienced surgeons may lead to increased complication rates (Newman, 1993)

Similar Waiting List Initiatives were conducted for general surgery at three hospitals in the Reading and West Berkshire regions of England. A staff surgeon was appointed and funded through Waiting List Initiative funding to carry out pre-operative validation clinics, to review all eligible patients, and to undertake most of the surgery. Overall, 723 patients were asked to attend one of 56 assessment clinics. Five hundred patients were provided with dates for surgery and 223 patients (31%) were removed from the waiting list. Among those removed from the list, 31 patients (14%) were removed temporarily and 192 patients (86%) were removed permanently for various reasons including failed to attend, unfit for anaesthetic, declined operation, moved or died. Approximately 95% of the surgery was for varicose veins. The total waiting list size decreased by 19% from 1,114 patients to 904 patients by the end of the Initiative and all waits longer than two years were eliminated. The number of patients waiting more than 1 year decreased 54% while the number waiting less than one year remained constant. The proportion of patients waiting for varicose vein surgery decreased from 65% to 40%. Conversely, the proportion of patients awaiting hernia surgery increased from 10.4% to 15% during the same time period. The authors concluded that despite a total reduction in waiting list size, patients treated for varicose veins were done at the expense of patients waiting for other surgeries (Umeh et al., 1994).

Waiting List Initiative funds were also used to create a more permanent solution to waiting lists. In Wales, a permanent general surgery treatment centre was established in 1990 to provide additional services to the entire region. The centre was comprised of 14 beds with a part-time consultant surgeon and junior physician support. Funding was allocated to provide a minimum of 800 hernia and varicose vein operations in the first year. Preference was given to those patients who had been waiting more than 1 year. Two pre-operative assessment clinics were held each week. A total of 1097 patients were assessed for surgery during the first year; 160 patients either failed to attend or were not able to attend and the remaining patients (n=937) were assessed. Overall, there were 750 operations performed with 60% for varicose veins and 35% for hernia repairs. The majority of patients (48%) were from the host district. The number of patients awaiting non-urgent general surgery (waiting < 1 year) decreased by 13.4% from 7261 (March 1990) to 6290 (March 1991). Likewise, the number of patients waiting more than 1 year for non-urgent surgery decreased by 8% from 2281 to 2099 during the same period. The investigators analysed changes in waiting list size for specialties without a treatment centre to control for the effects of external trends; waiting list size for non-urgent procedures in ENT and gynaecology both increased between March 1990 and March 1991. The general surgery waiting lists for three districts who made minor use of the centre, increased slightly during this time period. The authors concluded, therefore, that the centre was successful in increasing output and reducing waiting lists and, hence, recommended that this strategy should be universally adopted in the UK (Harvey et al., 1993).

In the Gwent Health Authority, funds from the Waiting List Initiative were used to employ a locum urological senior registrar between November 1989 and March 1990 in an effort to reduce urological waiting lists. Prior to the commencement of the Initiative, there were 231 patients on the urological waiting list. A letter was sent to each patient asking whether they wanted to proceed with the surgery or be taken off the waiting list. The majority of patients (68.8%; n=159) requested surgery, while 16.5% (n=38) declined the offer and 14.7% (n=34) failed to reply. Among those requesting surgery, 51 patients required minor surgery (e.g. circumcision, hernia repair, cystoscopy); these patients had been waiting between 1 and 51 months for surgery (median=5 months). They were all offered surgery at a satellite hospital where five beds were made available each week; only 68.6% (n=35) of patients attended and

the remaining patients defaulted on one or more occasions. The majority of patients ($n=108$) required major surgery (e.g. TURP, bladder neck incision); their waiting times ranged from 1 to 112 months (median= 21.5 months). All but 4 patients attended a pre-admission clinic and 84 patients proceeded to surgery. The authors concluded that the Waiting List Initiative successfully eliminated one consultant's waiting list in 5 months, partially due to pre-assessment evaluations of all patients waiting for care (Mobb et al., 1994).

A single national study was conducted by Newton et al. (1995) to investigate the effects of earmarked funding, introduced as part of the Waiting List Initiative, on waiting list size and waiting times. The purpose of the study was to determine how changes in the number of admissions from waiting lists and changes in the number of additions to the list are related to waiting list size and waiting times. The study was based on the use of national and Korner statistics for England (1987-94) and the districts of the former region of Oxford (1987-1991), for elective surgical procedures. Pearson's correlation was used to determine the association between quarterly changes in the number of admissions from waiting lists and total waiting list size, changes in the number of those waiting 1-2 years and over 2 years, and changes in the number of additions. Multiple regression analysis was used to control for simultaneous changes.

Nationally, the analysis indicated that changes in the number of admissions from the list were associated with changes in the number of additions to lists ($r=0.84$; $p<0.01$); that is, the more patients admitted from the list, the more patients were added to the waiting list. The anticipated inverse relationship was attained only when adjustments were made for additions to the list ($r=-0.62$; $p<0.01$). Decreases in the number of patients waiting from one to two years were significantly associated with increases in the number of admissions ($r=-0.52$; $p<0.01$); this demonstrated to researchers that the Initiatives were clearly aimed at reducing longer waits. The effects of earmarked funding were also analyzed for the Oxford region. Between 1988 and 1991, 44 waiting list initiatives were distributed among 25 of the 40 district specialties in the former Oxford region for a total value of £3.3m. Only 6 of the 44 initiatives resulted in an increase in admissions and a subsequent decrease in wait list size; in 11 cases, additional funding was followed by a decline in list size but no equivalent increase in

admissions; and in 27 cases, the waiting list size did not change or increased in the six months following the extra funds. Targeted funding for waiting lists did not lead to consistent effects on waiting list size. The authors conclude, therefore, that while an increase in admissions improves waiting times (i.e. decreasing the number of patients waiting one to two years), it does not lead to a decrease in wait list size due to increases in additions to the waiting list (Newton et al., 1995).

The other major component of the UK's efforts to address waiting lists was the Waiting Time Guarantee introduced as part of the Patient's Charter. There are no published studies which focus specifically on the effects of the guarantee. To date, policy evaluation has focussed primarily on changes in the national waiting list statistics (KH07). Table 5.3 presents information on waiting list size and waiting times since 1987, unadjusted for population growth or changes in age distribution. The total waiting list size has continued to increase but patients are waiting less time. The total number of patients waiting increased from 848,022 in September 1987 to 1.2 million in September 1997. The largest annual increase occurred between 1996 and 1997 when waiting list size increased by 13%. This is blamed partly on an increase in service utilization. Of the 1.2 million patients waiting, 570,000 were waiting for inpatient care and 636,000 were waiting for day case admissions.

As previously mentioned, the Waiting List Initiative intended to eliminate long waits (i.e. > 2 years), was introduced in 1987. The number of patients waiting more than 2 years decreased from 90,470 in 1987 to 43,517 in 1991. Further reductions were noted following the introduction of the Patient's Charter (1992), guaranteeing waits less than two years. The number of patients waiting more than two years decreased from 655 in September 1992 to 523 in 1994. The number dropped dramatically to 0 patients in 1995 following the revision of the Patient Charter, guaranteeing waits less than 18 months. But between September 1996 and 1997, the number of patients waiting more than 1 year increased more than three fold from 14,992 to 57,686. This followed a fairly steady decline since September 1994 (Dept of Health, 1998). There was an increase in total waiting list size across eight major specialty groups (general surgery, urology, trauma and orthopaedics, ENT, ophthalmology, oral surgery, plastic surgery and obstetrics and gynaecology). As of March 31, 1997, 75% of

patients on the waiting list for these procedures had been waiting less than six months and 49.7% of patients had been waiting less than three months. Only 2.7% of patients waiting at this time had been doing so for more than one year compared with 0.6% on March 31, 1996. Of those admitted to hospital as of March 31, 1997, 74% had been admitted within three months of being placed on a list and 98% were admitted within a year (Dept of Health, 1997 c).

Table 5.3: Waiting list size and waiting times for England, 1987 to 1997

Year	Total List	<12 months	12-24 months	> 24 months
Sept 1987	848022	638582	118970	90470
Sept 1988	900051	680122	128070	91859
Sept 1989	929056	710940	129992	88124
Sept 1990	957533	754793	131632	71108
Sept 1991	947842	789321	115004	43517
Sept 1992	939740	859159	79926	655
Sept 1993	1032038	961016	74699	408
Sept 1994	1071101	1008760	61818	523
Sept 1995	1040152	1012214	27938	0
Sept 1996	1097815	1082822	14992	1
Sept 1997	1207538	1149850	57686	2

Source: Department of Health. Country Report: The United Kingdom. NHS Executive Headquarters, 1998.

Waiting times for first outpatient specialist appointments were first reported in 1997 through the QM08 returns. As of September 30, 1997, 1.9 million patients were seen by an outpatient specialist following a written referral from their GP, representing 71% of all patients seen at this time. 11.6% of patients failed to keep their first appointment without giving notice the day before. Of those patients seen, 83% were seen within 13 weeks of their GP referral and 97% were seen within 26 weeks. The proportions varied by specialty with 91% of general surgery patients seen within 13 weeks compared with only 69% of trauma and orthopaedic patients (Dept of Health, 1997(d)).

The UK has adopted a multi-pronged approach to address the issue of waiting lists at a national level. National data on waiting lists have been collected for several decades in an effort to learn more about the phenomenon as well as to monitor changes in times, across regions and specialties. Targeted funding and waiting time guarantees reflect a more direct strategy adopted since the late 1980s to reduce long waiting times. Based on current statistics, these strategies appear to have had some effect on reducing the waiting times of patients to less than two years. It is not readily apparent, however, to what extent (if any) each policy is responsible for these effects.

Both policies were adopted in part to reduce waiting list size and waiting times patients awaiting non-urgent care. The results of selected studies indicate that targeted funding used as part of the Waiting List Initiative, for the most part, reduced waiting list size in the short-term. These findings were consistent across studies which did not consider new patients added to the waiting list during the time of the Initiatives. However, when new additions to the waiting list were considered simultaneously, a different result emerges: total waiting list sized increased during the period of additional funding. These findings indicate that targeted funding, in certain cases, could lead to an overall increase in waiting list size, clearly not the desired effect of such a policy (Drake-Lee, 1991; Newton et al, 1995).

The effects of the waiting time guarantee are not as clear. It appears that waiting times have decreased since the introduction of the guarantees, most notably with the elimination of waits longer than 2 years. Some argue, however, that the success of the initial waiting time guarantees adopted in the Patient's Charter of 1992 was due to the effects of the targeted funding policies adopted in the late 1980s as part of the Waiting List Initiatives (personal communication J. Yates). The eliminations of waits longer than 2 years, however, have been sustained beyond 1993 when the Waiting List Initiative ceased. Furthermore, it may be that gains made in reducing the number of patients waiting more than two years were achieved at the expense of patients requiring more urgent care; while resources have been used to treat patients with long waits, newer cases have had to wait longer (Yates, 1991; Appleby, 1993; personal communication with M. Rigg). This may explain the increase in the number of cases waiting 12 to 24 months.

The policies adopted in England are comprised of a combination of increased funding and waiting time guarantees. While a range of policies may be more effective to address waiting list problems than a single strategy, it becomes increasingly difficult to separate out the effects of each strategy. On a final note, waiting lists have once again emerged as an issue since the rise of the Labour Party began governing. A new committee has been struck to consider new policy options and strategies to address the rising number of patients awaiting care. The committee was expected to have their first meeting in the early part of 1998.

7.1.4 The Role of Private Sector Health Care

Private sector health care has long been proposed as a solution to waiting lists (Kennedy, 1997; Mulawka, 1997). Proponents of private health care argue that the introduction or expansion of private sector health care will relieve the pressures on the public system and as patients sought in the private system, more resources would be available for those remaining in the public system. In England, policy options include the provision of publicly funded subsidies to patients willing to receive care in the private sector (Cullis et al., 1983; Cullise et al., 1985). While private sector health care was not explicitly introduced to address the NHS waiting list problems, England's experiences with a mixed system provide valuable insight regarding the potential effects of such a system on public sector waiting lists.

There is limited descriptive and anecdotal information which suggests that private sector health care adversely affects public sector waiting lists (Richmond, 1996; Light, 1997). Harvey (1993) compared waiting lists (inpatient and outpatient combined) between two groups of surgeons, one group (n=6) undertook no private practice and the other group (n=7) partook in some private practice. Physicians with some private practice demonstrated significantly longer median waiting lists (286) than the fully public sector physicians (111). The generalizability of the results are clearly limited but they provide some indication of the potential relationship between private sector care and public sector waiting lists (Harvey, 1993).

Yates (1995) conducted investigated the practices of those physicians practising in the private sector. One of the issues Yates considered was the relationship between waiting list size and

waiting times and private sector health care for selected procedures. For Birmingham, routinely collected waiting list data for the NHS were compared with data collected via telephone enquiries for private sector care. The waiting times for an orthopaedic appointment in an NHS clinic was between 4 and 115 weeks (mean: 33 weeks) compared with waiting times between 1 and 7 weeks (mean: 3.5 weeks) in private clinics. To gain a more representative sample, Yates compared the waiting times of 169 orthopaedic surgeons across England and 66 ophthalmologists practising privately to NHS clinics. The mean waiting time for orthopaedics was 2 weeks in the private clinics compared with 25 weeks in the NHS. The results were similar for ophthalmology where the average waiting times were 2 weeks compared with 19 weeks in the NHS (Yates, 1995).

Yates also investigated the association between NHS waiting times and the number of private beds across regions for 1989. With one or two exceptions, those regions with a higher private sector bed capacity also demonstrated a higher proportion of patients waiting more than one year for health care in the NHS. A region with over 40 private beds per 100,000 had over 35% of patients waiting more than one year compared to regions with less than 10 private care beds per 100,000 with less than 20% of patients waiting more than one year. Due to the nature of the analysis, causality cannot be determined, but the results do provide some insight regarding the relationship between private sector care and public sector waiting lists (Yates, 1995).

While the evidence is limited and descriptive in nature, it appears to suggest that private sector health care may lead to significantly different waiting times and subsequently, inequalities in access to health care. The evidence also suggests that waiting lists and waiting times in the public sector may be affected by the amount of private practice. The issue of private health care and waiting lists clearly requires further investigation.

7.2 Sweden

Like other countries with largely publicly funded health care systems, waiting lists in Sweden were, at one time, considered a serious problem. Since the late 1980's, Sweden has adopted various national policies to address its waiting list situation.

7.2.1 Waiting List Policies

Financial Incentives

Between 1987 and 1989, the Government and Federation of County Councils agreed to compensate hospitals if they worked overtime to provide additional surgery for coronary artery bypass, hip replacement and cataract. Reports suggest that this had little effect on waiting times (Hanning et al., 1996).

In 1989, an agreement was reached among six different specialty departments to increase accessibility and capacity. This involved the comparison of resources, output and performance indicators across the six departments in an effort to identify problem areas. The agreement also included additional funding for local projects aimed at reducing the bottlenecks and addressing other throughput problems. The effect of the agreement was not clear.

Waiting lists continued to vary across sites and many remained long.

Waiting Time Guarantee

In January 1992, the Swedish government and the Federation of County Councils introduced a waiting time guarantee for 12 surgical procedures. The procedures were selected based on the following criteria: (1) waiting created a problem, (2) the treatment methods are well established, (3) results are measurable, and (4) the clinical benefit is high. The guarantee stated that patients must be offered surgery within 3 months of being placed on a waiting list signifying decision to treat. If the hospital could not provide the service within this time frame, patients had a right to be treated by another hospital or by a private clinic at the expense of the home hospital. This policy would hopefully encourage the transfer of patients to hospitals with shorter waiting lists since earlier studies indicated a high degree of variation in waiting times among hospitals. A booklet was produced by the National Board of Health to inform hospitals, clinicians and patients about the guarantee. The policy was initially to be in

force for only one year and a grant of 500 million SEK (\$70 million US) was targeted to help hospitals meet the targets. The grant was allocated to the county councils on a capitation basis. Ultimately, the decision was made to extend the policy from 1993 to 1995. Additional resources, however, were not allocated for these years (Hanning et al., 1996; Hanning et al., 1998).

7.2.2 Effects of Waiting List Policies

A limited number of published reports have evaluated the effects of these policies. Hanning et al. (1996) evaluated the policies using waiting list data obtained through a national hospital survey since no national waiting list statistics were collected at the time. The outcome measures used include the number of patients on the waiting list eligible for the guarantee, expected wait time for the next patient, and the number of procedures performed during the specific time period. The first survey was conducted in April 1991 to obtain some “before” measures. It has continued annually. An additional survey of hospital and department managers was used to obtain more information regarding the effects of the guarantee.

Aggregated measures of waiting list size for patients with and without a guarantee were used to assess the effects of the policy. The total number of patients awaiting surgery for one of the 12 selected procedures decreased from 51,100 patients in January 1992 to 40,300 on December 31, 1992, reflecting a 21% decline. This decline, however, began prior to January 1992 when the decision to adopt the policy had been made but was not yet enforced; between August 1991 and December 1991, the total number of patients waiting for one of the 12 selected procedures decreased dramatically from 60,000 to 50,000. By December 1993, two years after the adoption of the policy, the number of people waiting had increased to 41,500. A similar pattern was noted when only those patients with waiting time guarantees were considered.

Changes in waiting times were also noted. In August 1991, the waiting time for almost half of new patients exceeded 12 weeks; by April 1992, nearly 90% of patients were waiting less than 13 weeks. After one year, the situation improved even more with 95% of waiting list patients waiting less than 13 weeks. After two years, however, this had slipped slightly with only 91%

of waiting lists able to guarantee new patients care within 13 weeks. There were a considerable number of patients who waited longer than 13 weeks because they chose to wait longer rather than go to another hospital.

The number of procedures performed also increased during 1992, with the total number of procedures covered by the guarantee increasing from 161,300 to 180,100. The authors conclude that the guarantee has been successful in reducing waiting lists and waiting times, primarily through an increase in production. The concern, however, is the extent to which the guarantee has contributed to these declines compared to concurrent changes occurring within the Swedish health care system, including policies aimed to improve efficiency, introduce new technologies, reduce bedblockers and introduce new administrative systems (Hanning et al., 1996).

Additional evaluations were conducted to determine the effects of the waiting time guarantee policy on cataract surgery. The National Cataract Register (NCR) was established in late 1991 to evaluate the effects of the policy. In 1992, 81% of all cataract surgeries performed were recorded by the NCR and 92% were recorded by 1993. The waiting time is defined as the time between listing for surgery and admission for surgery. In 1992, 66% of patients with priority had their surgery within 3 months; this figure rose to 71% by 1993; however, this figure varied greatly among different eye clinics, from 40% to 99%. The waiting time guarantee was restricted to patients with priority (i.e. those with visual acuity of 0.5 or less in the better eye). In 1992 and 1993, 62.6% and 59.1% of all cataract patients respectively were considered priority cases. The proportion of priority patients within each clinic also varied with some surgical departments reporting 95% priority patients while others reported 50%. Additional analyses were conducted to investigate this level of variation. The authors concluded that the NCR has achieved a high participation rate in its first two years. This is due in part to an endorsement by the Swedish Ophthalmological Society and the fact that all eye clinics were asked by the authorities to report to the NCR as part of the agreement between all regional health authorities. The effect of the waiting time guarantee on cataract surgery waiting times was clearly mixed (Lundstrom et al., 1996).

By 1995, the proportion of patients treated within the time guaranteed decreased to 59%. As mentioned previously, the guarantee was extended only to those patients with a visual acuity of less than 0.5 in the better eye; the guarantee could also be extended to patients with “special circumstances”. The proportion of patients meeting this criteria decreased from 54% in 1991 to 40% in 1995. This would, one expect, lead to a decrease in the number of patients covered by the guarantee. However, there was an increase in the total number of priority patients due primarily to an increase in the number of patients classified as “special circumstances” (12.4% in 1991; 21.8% in 1995). The number of units that managed to provide surgery within 3 months for 75% of their patients decreased from 21 of 33 units in 1993 to only 16 of 33 units in 1995. The proportion of priority patients ranged from just over 40% in one unit to close to 90% in another and the proportion of priority patients treated within the 3 month guarantee ranged from less than 40% to close to 100%. The researchers hypothesized that the variation in guarantee achievement could be due to one of two factors: operation rates or stricter prioritization of patients. Data were obtained for 27 units and averages were calculated for years 1992 to 1994. The association between average surgical rate and average percentage of priority patients treated (i.e. goal achievement) within three months was positive but not significant ($R^2=0.07$; $n=27$); furthermore, the units with the highest surgical rates were not the ones with the best goal achievement. The association between the proportion of patients with priority status and priority patients treated within 3 months was negative ($R^2=0.39$; $n=27$), implying that the units with more priority patients were less likely to achieve the guarantee goal. The authors concluded that overall, waiting lists and waiting times improved for cataract surgery as a result of the guarantee policy. The positive effects, however, were short lived since waiting list size and waiting times were increasing as of 1994. The variation in goal achievement among the units was a result of a complex interactions of production, indications and priorities (Hanning et al., 1998).

Like the UK, Sweden adopted a waiting time guarantee approach supported by the availability of additional resources. The Government had hoped that waiting lists and waiting times would decrease as a result, in part, of increased production and changes in referral patterns that would redirect patients to providers with shorter waits. After two years, the policy appears to have had a positive effect on waiting list size. The positive effects of the guarantee

appear, however, to be limited to the short-term. Waiting lists and waiting times were increasing by the end of 1994 and considerable variation remained across hospitals. The effects of the policies did not seem to extend beyond the period in which additional resources were made available to support institutions in their efforts to ensure patients received care within the time guaranteed.

7.3 Australia

Faced with increasing waiting lists during the late 1980s, the State of Victoria in Australia also sought to develop policies that would decrease waiting lists and waiting times on a permanent basis (Beaumont, 1993). Researchers and policy makers in this state argued that policies which focus on increased spending, improved monitoring or more stringent admission criteria simply would not effectively address the waiting list situation. Instead, they believed that policies should address those incentives which encourage hospitals and physicians to maintain waiting lists. In Victoria, as in most of Australia, hospitals use long waiting lists to get more resources and physicians use them to encourage patients to seek care in the private sector. What was required, therefore, were policies which represented binding contracts with providers and which linked resources to specific activities.

7.3.1 Waiting List Policies

The strategy in Victoria involves three distinct steps: (1) the development of priority criteria, (2) linking hospital funding to specific case mix, and (3) linking financial incentives to the treatment of patients on the waiting list. In 1991, the Victoria Health District invited surgeons to participate in the development of a classification system to prioritize patients on the waiting list according to specialty-specific criteria for clinical urgency. As a result, patients on a waiting list as of January 1, 1992 were placed in one of the following categories: (1) urgent (n=2,066) with admission within 30 days, (2) semi-urgent (n=10,103) with admission within 12 weeks, and (3) non-urgent (n=14,154). In July 1993, hospital funding was changed from a global funding formula to one based on case mix. Global budgets had been based on historical patterns and broad goals, a method deemed inadequate to change practice behaviour. Case mix funding was introduced so that hospitals would be funded according to the number and type of patients treated. The casemix is based on the 526 Australian National Diagnostic

Related Groups (AN-DRGs) and determines 50% of the hospital budgets. Finally, a financial incentive program was introduced during the 1993/94 fiscal year to provide additional funding to those hospitals who gave priority to patients on the waiting list. Hospitals were entitled to funds from the “additional throughput pool” if they had cleared their urgent waiting list cases by December 31, 1993 and additional funds were available if semi-urgent cases were cleared by April 1, 1994 (Duckett, 1995; Street et al., 1996).

7.3.2 Effects of Waiting Lists Policies

The results of the policies were positive. Overall waiting lists decline dramatically following the introduction of the new incentive structure. The number of urgent cases on the waiting list declined from 1298 in July 1993 to 195 in July 1994 with only 5 cases waiting more than 30 days in July 1994 compared to 849 patients in 1993. The number of semi-urgent cases declined from 12,115 to 8506 during the same time period. The number of non-urgent cases increased by 8 cases to 15340 in July 1994. The authors concluded that policies which provide incentives for hospitals and physicians to manage their waiting lists can be successful (Duckett, 1995; Street et al., 1996).

The Australian approach is clearly a departure from the traditional strategies used to date. Funding structures and mechanisms were altered to address the waiting list situation rather than simply increasing the total funds provided. Hospitals and physicians were provided with incentives to change their practices and management of patients. There may be, however, effects not considered in the evaluation conducted by Street et al. For example, additional funds were provided to hospitals which *cleared* their waiting lists; this may in fact provide an incentive for providers to underestimate need and keep waiting lists short. Furthermore, the cost of clearing waiting lists for some patients may be borne by other patients. Urgent cases are likely to represent the smallest proportion of patients and, therefore, represent a small waiting list relative to longer waiting lists for non-urgent cases. It is possible that hospitals will seek to put patients on, then clear, these shorter lists in order to be eligible for additional funding. They may also take on new urgent cases to create new waiting lists. As noted previously, admissions from waiting lists is positively associated with increases in waiting list size (Goldacre, 1987). Hospitals stand to gain, therefore, by focussing their efforts on the

smaller number of urgent cases, so long as they can continue to create new urgent patient lists.

7.4 New Zealand

7.4.1 Waiting List Policies

Unlike the previous examples, New Zealand has adopted a direct management approach to the issue of waiting lists, through the development of priority criteria. This process began at the local level for coronary artery bypass patients in an Auckland hospital. Several ranking systems were compared to determine which would lead to a more equitable allocation of patients. The ranking systems compared in the study include the Green Lane Hospital (GLH) scoring system, the Canadian consensus system (developed by Naylor et al.), and clinical priority as determined during a weekly consensus meeting among cardiologists and cardiac surgeons (Agnew et al., 1994).

The search for priority criteria quickly took on a national focus. In 1992, the New Zealand health care system underwent a dramatic restructuring, in part to introduce more accountability within the publicly funded system. The existence of long waiting lists has long been a problem in New Zealand. As part of the restructuring process, a national health committee was struck to investigate the types of services that should be publicly funded and processes to address waiting lists. The project was jointly sponsored by the National Advisory Committee on Health and Disability and the four regional health authorities. The national health committee recommended that the system move away from a system of waiting lists to a system of specific booking times for patients which would provide patients with a better understanding of the length of wait prior to surgery. To achieve this goal, they set out to develop a set of criteria to achieve the following: (1) to assess patient need for surgery, (2) to ensure consistency and transparency in the provision of surgical services, and (3) to provide a basis for describing the kinds of patients who will and will not receive surgery under various levels of funding. A modified Delphi technique was used to reach consensus. A range of clinical and social factors (e.g. age, threat to independence or care of dependents, time spent on waiting list) were used to establish priority criteria. Criteria have been established for the following procedures: cataract, CABG, hip and knee replacement, cholecystectomy, and

tympanostomy tubes for otitis media with effusion. In May 1996, the Minister of Health created a new fund (\$90 million US) aimed to reduce waiting times and waiting lists. Access to the new funds was conditional on the adoption and use of the new priority criteria (Hadorn et al., 1997; Hadorn, 1997)

7.4.2 Effects of Waiting List Policies

Evaluation of the development process and use of the priority criteria to date has focussed primarily on coronary artery bypass surgery. The priority ranking systems mentioned above were compared in a study conducted by Agnew et al. (1994) based on 260 patients awaiting non-emergency surgery as of September 1, 1993. Patients were originally prioritized via consensus among surgeons and cardiologists. The scoring systems were applied retrospectively. The results indicate that when similar items were compared (i.e. symptoms, coronary anatomy and stress test) between the GLH system and the Canadian system, there was a high degree of correlation ($r=0.9179$). However, a weaker association ($r=.6869$) was noted when the Canadian system was compared to the expanded GLH scoring system that includes factors such as age, employment status and surgical risk. Overall, the Canadian system assigned higher priority than the GLH system; the Canadian system gave 150 patients higher priority. The expanded GLH was also compared to the rankings assigned by the physician group. Both systems were in agreement regarding the need for surgery but did not agree on priority rankings for 51 patients. The authors conclude that a scoring system should be used only as an aid for surgeons and cardiologists charged with making priority decisions. They argue that scoring systems cannot and should not be used as a replacement for clinical judgement (Agnew et al., 1994).

Some clinicians were also concerned that the government would use the criteria to select an arbitrary cut-off point below which surgery would not be funded. Many clinicians believed that the real problem was inadequate funding. Despite these concerns, they were committed and participated fully in the process. It is believed that this level of participation was due in part to the fact that clinicians realized that decisions about priority were not made consistently; furthermore, they were eager to develop a set of objective measures for symptoms and functional status that the government could understand. The group selected to develop the

criteria consisted of 7 cardiologists, 4 cardiac surgeons, and 2 general practitioners. The panel reviewed results from published works as well as additional comments from other cardiologists. The Delphi method was used to determine the final set of criteria which included degree of coronary artery obstruction, angina, exercise stress test, ability to work, care for dependents or live independently. Each criterion was assigned a weight with a total maximum score of 100 points.

Overall, 260 patients from three different hospitals were assessed. Total priority scores were calculated for each patient, and physicians were asked to provide a reasonable waiting time for each patient that would later be used as the outcome variable in the subsequent analysis.

Regression analysis was used to determine the set of criteria weights resulting in the highest correlation between priority ratings and judgements of reasonable waiting times. The variable coefficients were used as weights to revise and modify the existing criteria. The new criteria were then used to conduct a clinical audit of the 662 patients then awaiting CABG. An experienced nurse reviewer examined the clinical records of all patients and abstracted the information necessary to determine priority scores. The data were also used to communicate to politicians and policy makers a description of the average patient awaiting surgery within each five-point band of the priority scales. Median measures of various factors were used to describe the “average” patient within each priority band. For example, the majority of patients were given a priority score between 25 and 29 points; these patients suffered from coronary artery disease in three vessels, a class II angina, a mildly positive exercise stress test and no threat to their ability to work or care for dependents. Finally, the information was used to determine a cut off point to indicate when surgery should be considered. The clinicians agreed that a clinical threshold of 25 points should be used to determine the level of public funding for CABG (Hadorn et al., 1997).

The priority criteria developed via this process were then compared to the Canadian priority ranking scheme developed in Ontario. The study had three objectives: to assess baseline characteristics and waiting times of patients awaiting CABG surgery; to assess clinical events during the waiting times; and to compare various scoring methods. The study was based on a retrospective review of 88 consecutive cases listed for surgery between July 1 and December

31, 1993 at Christchurch Hospital in New Zealand. Waiting times were defined as the time between the date of initial referral for surgery and the date of the surgical procedure or December 31, 1995 if the patients did not have surgery by this time. The Canadian Health Association classification was used to determine the severity of angina. The New Zealand scoring system (Score: 1-100) was used to assign priority and the Ontario system (Score 1-7) was used retrospectively to assign priority. The median score assigned by the Ontario system was 5.25 and the median score assigned by the New Zealand scoring system was 54. Overall, 79 patients underwent CABG with a median waiting time of 92 days. One patient sought care privately. Only 34% of patients received care within the time recommended by the Ontario guidelines. One patient died while waiting at home, one patient suffered a myocardial infarction and 17 patients were readmitted to hospital with unstable angina. Time to readmission was not correlated with the New Zealand or Ontario scores, the coronary score, the site of coronary stenosis or the left ventricular ejection fraction. The results of this study were compared to a study conducted in Ontario (1991-1993) by Naylor et al. (1995). This comparison suggested that patients wait far longer in New Zealand than in Ontario. The authors concluded that the long waiting lists in New Zealand were a direct result of chronic underfunding and low intervention rates (Doogue et al., 1997).

7.5 Canada

Like those countries reviewed above, Canada is also struggling with the issue of waiting lists. Since the primary responsibility for health care lies with the provincial and territorial Ministries of Health, policies and strategies adopted to address the issue of waiting lists might be expected to occur at this level. The following section provides a review of the recent strategies adopted at the national or at the level of regional health authorities with devolved responsibilities and provincial levels to address various waiting list situations, based on information available from published or unpublished literature.

Several studies previously discussed have attempted to collect national data on waiting lists and waiting times for specific procedures (O'Keefe, 1982; Jacobs et al., 1990; Higginson et al., 1992; Higginson et al., 1994). The only current source of national information is the waiting list data compiled annually by the Fraser Institute. The Fraser Institute has consistently argued

that waiting lists represent a mechanism of non price rationing that carry with them significant social costs. According to the Institute, rationing, is in part, a consequence of the amount of resources allocated to the health care sector (Miyake et al., 1993; Ramsay et al., 1994, 1995, 1996, 1997). Institute researchers argue that allowing a parallel private system would clearly address the waiting list problems plaguing health care in Canada (Anonymous, 1997; Mulawka, 1997).

The primary purpose of the reports is to collect information regarding hospital waiting lists for a range of specialties including plastic surgery, gynaecology, ophthalmology, otolaryngology, general surgery, neurosurgery, orthopaedics, cardiology, urology, and internal medicine. The first study was conducted in 1990 and was limited to physicians in British Columbia (Globberman et al., 1990). The second study was expanded to include five provinces (BC, Manitoba, Newfoundland, New Brunswick, and Nova Scotia) (Walker et al., 1992); all subsequent studies have been conducted on all 10 provinces (Miyake et al., 1993; Ramsay et al., 1994; Ramsay et al., 1995; Ramsay et al., 1996; Ramsay et al., 1997).

The studies were based on self-reports from random samples of physicians and in general, achieved response rates of between 25% and 30%. Physicians were asked to report waiting times for new patients for a range of surgical procedures and, in later editions, for specific diagnostic tests. Initially, average waiting times were reported. In 1995, the Institute began to report median waiting times after being criticized for their use of means when waiting time data were skewed (CHA, 1994). The reports also provided information on the estimated total number of patients waiting for selected specialties and procedures for each province. Waiting list size was estimated by dividing the average waiting time by 52 and then multiplying this amount by the total number of persons undergoing the procedure annually as reported by Statistics Canada (Ramsay et al., 1994, 1995, 1996, 1997). The methodology used to estimate waiting list size is problematic for several reasons. First, the measure is dependent in part on an accurate estimate of waiting times; if waiting times are overestimated, so too will estimates of waiting list size be over-stated. The methodology is based on the use of average waiting times which, as previously discussed, overestimates waiting times due to the skewed nature of waiting time data. It is likely, therefore, that estimates of waiting list size are

inflated. Second, the wait list estimates are calculated based on the number of procedures performed annually. The data representing utilization, however, do not correspond to the same time period as the waiting time data; in the latest report (1997), for example, utilization data were obtained from Statistics Canada's "Hospital Morbidity and Surgical Procedures 1993-1994" report. The methodology is based on assumption that utilization has not changed since this time and on the assumption that the number of procedures performed remains constant throughout the year. It also assumes that there were no urgent patients who were never placed on a waiting list.

A secondary goal was to comment on whether waiting times for patients were "reasonable". Starting with the 1994 report, physicians were asked to report "reasonable" waiting times for the range of procedures. This information was compared to actual waiting times as reported by the same physicians. Not surprisingly, reasonable waiting times were, in general, reported to be less than actual waiting times. The researchers have consistently concluded, therefore, that patients wait too long for health care services (Ramsay et al., 1994, 1995, 1996, 1997). Without objective criteria and measures of clinically acceptable waiting times, subjective reports of "reasonable" waiting times are problematic. First, the measure does not distinguish between types of patients and clinical severity. Second, if physicians believe that waiting lists and waiting times are generally a problem, they are more likely to report "reasonable" waits that are shorter than actual waits.

Finally, the reports provided information regarding the association between waiting times and health care expenditures. As previously mentioned, the Institute has consistently argued that waiting lists represent mechanisms to ration health care resources. Their long standing hypothesis, therefore, is that there is an inverse relationship between health care expenditures and waiting lists size and waiting times. In other words, when resources are inadequate to keep up with the demand for health care, waiting lists and waiting times will be long. To test this hypothesis, the Institute has compared the difference in provincial and national adjusted average per capita health expenditures average waiting times across provinces. Since 1994, the Institute has reported that, overall, Ontario has consistently performed better than other provinces regarding waiting lists. The province has demonstrated lower than national average

waiting times as well as higher than average per capita expenditures. The Institute concluded, therefore, that Ontario's success has been due primarily to increased spending on health care (Ramsay et al., 1994, 1995, 1996, 1997). The results of these analyses, however, have been clearly mixed. British Columbia, for example, has consistently demonstrated higher than average per capita expenditures as well as higher than average waiting times for 1994, 1996 and 1997 (Ramsay et al., 1994, 1996, 1997). In the most recent study, Health Canada expenditure data from 1994 and compared with the latest waiting time data. Ontario and Newfoundland were the only provinces demonstrating higher than average per capita expenditures and lower than average waiting times; Alberta and British Columbia both demonstrated higher than average expenditures and higher than average waiting times. Quebec and Manitoba demonstrated lower than average expenditures and lower than average waiting times (Ramsay et al., 1997). The association between health care resources and waiting times is not as simple as the Institute may be suggesting as should be clear from the extensive literature reviewed earlier.

Since health care is primarily within the domain of provincial governments, policies and strategies adopted to date to address waiting lists have occurred largely at the provincial level. The absence of information from all provinces is due in part to a lack of information in the published and/or unpublished literature and does not necessarily reflect inactivity regarding policies on waiting lists.

7.5.1 Ontario

Ontario has adopted a multi-pronged approach to waiting lists for selected procedures, with a primary focus on cardiac care.

Targeted Funding

Like other governments, Ontario has allocated considerable funding to reduce waiting lists and waiting times, primarily for cardiac care. In 1997, for example, the Ministry of Health allocated \$35 million to cardiac services (CNN, 1997; Ontario Ministry of Health, 1997). The province has also increased funding to address waiting lists for cancer, orthopaedics, MRI, and dialysis.

Waiting List Management

Perhaps the most significant gains to date, as documented in the literature, have been in cardiac care where clinicians, researchers and policy-makers have adopted various strategies to manage waiting lists for selected procedures. The efforts were sparked in part by a waiting list "crisis" in Ontario for coronary artery bypass surgery in the late 1980s. Reports in the media of patients dying while awaiting surgery, as well as continually lengthening waiting lists, brought the issue to the fore. A multi-pronged approach was adopted to address the waiting list problem, including an increase in funding to improve the capacity of the system, the designation of nurses to monitor patients awaiting surgery, changes in the booking system to prioritize more urgent cases, changes in case selection criteria, and eventually, the development of a provincial registry (Naylor et al., 1991).

Formal management of the cardiac waiting list began at the local level with the establishment of the Metropolitan Toronto Triage and Registry Program in 1988. The Registry was established to coordinate access to cardiac services through a "one-number-to-call" system. Following the events in the late 1980s, the Ministry sought to expand this program to the provincial level. Considerable efforts were then focussed on the development of strategies to manage waiting lists, including the establishment of a central registry and the development of priority criteria. The Cardiac Care Network of Ontario (CCN), formerly known as the Provincial Adult Cardiac Care Network (PACCN), was established in 1990. The Network has a two-fold mandate: to coordinate patient care for patients awaiting cardiac surgery or catheterization and to act as an advisory body to the Ministry of Health. The Network is currently comprised of eight surgical centres performing catheterization and angioplasty procedures in addition to four cathing centres. Each centre has a nurse coordinator who is responsible for collecting relevant data for each patient as well as locating a suitable and willing surgeon or interventional cardiologist who will then communicate directly with the referring physician. The Registry, therefore, is used to actively manage patients, providing relevant patient information to clinicians as well as providing information regarding physician availability to patients. Since its inception, the CCN has created an information system and database, and established waiting list management, system integration and information exchange between patients and physicians (CCN, no date). Since 1994/95, the number of

patients treated through the CCN has increased steadily from 8,262 in 1994/95 to 9,405 in 1996/97 (CNN, 1997).

One of the most significant contributions of the CCN was the development of the urgency rating score (URS), a 7-point rating scheme used to prioritize patients awaiting coronary revascularization (1=Emergency and 7=Markedly delayed). The URS was developed by a panel of cardiologists and cardiac surgeons. Each panel member reviewed and rated 438 hypothetical cases to determine maximum acceptable waiting times. A regression model was used to determine weights for each clinical factor used to create the URS. The scoring system is comprised primarily of three clinical factors which account for 90% of the URS: symptom status, coronary anatomy and ischemic jeopardy (Naylor, 1990; Naylor 1991; Naylor et al., 1991).

A similar process was used to determine priority rating criteria for coronary angiography. An expert panel consisting of 10 cardiologists working in both teaching and community hospitals was selected. Members of the panel were provided with 354 case scenarios representing various combinations of clinical factors affecting urgency for angiography. Each member was asked to rate the level of urgency using the 7-point urgency rating time scale (1=Within 24 hours; 7=No urgent need) to reflect the maximum acceptable delay for angiography for each case. The major determinants of urgency identified in the process included symptom class (as defined by a modified version of the Canadian Cardiovascular Society grading for angina pectoris), results of an exercise stress test and results of imaging studies. These factors together explained approximately 95% of the variation in urgency scores. At least 5 of 10 panelists agreed on the rating score in 85% of the cases and 7 of 10 panelists agreed in 29% of the cases (Basinski et al., 1992).

Similar efforts have been underway to adopt a management approach to deal with waiting lists for hip and knee replacement. As previously outlined, patients often suffer various adverse effects when waiting for care and this is especially true for chronic conditions in which prolonged delays could lead to increased pain and decreased mobility. A panel of clinicians including orthopaedic surgeons, rheumatologists, general practitioners, epidemiologists and

physiotherapists was assembled to develop a set of criteria to identify candidates for hip and knee replacement and to assign priority on the waiting list once surgery has been deemed appropriate. There is currently no high quality evidence on clinical indications for the elective procedures and the variation in referrals for hip and knee replacement and the lack of prioritisation of patients indicate a need for such an exercise. The development of the criteria are based on the RAND Delphi method, which relies on appropriateness ratings of abbreviated case scenarios, by a multidisciplinary panel of experts. The development of case scenarios was preceded by a review of the literature and existing clinical evidence. The panel then met to determine a list of factors that affect surgical referral and/or timing of surgery (e.g. pain, dysfunction) and various instruments were selected to determine the importance of level of the factors. Clinical factors commonly used by surgeons were sought to determine urgency rating and priority for waiting, including functional capacity, pain levels, and functional class. Overall, 120 case scenarios were rated for appropriateness (7 point scale) and 42 for waiting list priority (4 point urgency scale). Agreement among the panelists regarding ratings was 92.5% for appropriateness and 73.8% for urgency scenarios. The authors conclude that these criteria can be used to determine appropriateness of surgery and to assign priority for waiting (Naylor et al., 1996).

Effects of Waiting List Policies

Various studies have been conducted to assess the effects of the strategies adopted in Ontario to deal with waiting lists for cardiac care. The first concern was whether surgeons had accepted and adopted the rating schemes described above. A study conducted by Naylor et al. (1992) investigated the extent to which physicians had accepted the URS for coronary revascularization proposed by the expert panel. Hypothetical patient scenarios (49) representing a range of combinations of clinical factors were sent to cardiovascular specialists (n=122; 60% response rate) via a mailed survey in December 1989. The survey included, among other things, background information regarding the panel process as well as the URS scoring guide. Physicians were asked to read the material but were urged to rate the scenarios as they saw appropriate. For most cases (48), at least 75% of urgency ratings fell within 2 contiguous points on the rating scale. Symptom status was the primary factor determining waiting time. The authors concluded that physicians had assessed hypothetical patients in a

similar way and in accord with appropriate queue forming criteria. This provided evidence that physicians had indeed accepted the rating scheme proposed by the expert panel (Naylor et al., 1992).

One of the expectations was a decrease in the number of adverse events experienced in patients awaiting care since they would be “managed” through the CNN. The purpose of the study conducted by Naylor et al. (1993) was to determine the frequency of major adverse outcomes in patients waiting for coronary revascularization; to match physician estimates of urgency ratings, computer generated urgency scores and patient waiting times; to determine the changes in waiting times as capacity for surgery changes; and to evaluate the effect of choice of procedure and surgeon on waiting times. The study sample included all patients (n=571) referred to a central referral office in Toronto by cardiologists from hospitals without on-site revascularization between Jan 3, 1989 and June 30, 1991. 496 patients were accepted for the study. Relevant demographic and clinical information was provided to the referral centre by the cardiologist.

During the course of the study there were 5 fatal cardiac events and 3 non-fatal events. There was a positive association between physician urgency scores and waiting times ($r=0.46$) (i.e. longer waiting times and higher urgency scores meaning the patients were less urgent) and the computer generated scores and waiting times ($r=0.57$). There was a significant decrease in average waiting times when waiting times were analysed for each quarter of the study period. In 20% of the cases, a specific surgeon or an intervention cardiologist was specified; the mean waiting time for patients who did not specify a preference was 22.73 days compared to 35.31 days among patients who did specify a preference. The authors concluded that fatal outcomes among preoperative patients are uncommon if patients are properly prioritised. Furthermore, the positive association between urgency score (with higher scores denoting less urgency) and waiting times indicated the benefits of assigning clinical priority. Finally, additional resources led to a decrease in waiting times, allowing for more cases to be done within the reasonable waiting times assigned; preferences for surgeons may lead to longer waiting times (Naylor et al., 1993).

A population-based study was conducted to determine the outcomes for 8517 patients leaving the CCN between October 1991 and July 1993. For each patient, information is provided regarding waiting time (i.e. time from registration to surgery) and acuity score (i.e. defined by clinical characteristics). Only 3.2% of patients experienced cancelled or delayed surgery and 0.4% of patients (n=31) died while on the waiting list. Among those receiving surgery, the distribution of waiting times was skewed with a median waiting time of 17 days. A multivariate analysis conducted to determine the most significant factors contributing to waiting times revealed that symptom status was the most significant factor, followed by anatomy. Once controlled for clinical factors, waiting times varied by hospital. The authors conclude that patients waiting for surgery rarely suffered critical events or extreme delays and individual waiting times were reflective of patient acuity (Naylor et al., 1995).

Based on activities to date, it is evident that Ontario has adopted policies and strategies which aim to manage waiting lists. Additional funding was and continues to be allocated to address waiting lists primarily for cardiac patients. In addition, extensive efforts have focussed on methods to appropriately select patients for care and prioritize them based on need. It appears that these strategies have been successful in managing patients on the waiting list. There is little information, however, on the their effect on waiting list size and/or waiting times.

7.5.2 British Columbia

British Columbia has recently devoted considerable effort to addressing the waiting list situation in the province. As in Ontario, waiting lists gained increased attention with media reports concerning lengthy waiting lists for cardiac surgery and deaths among patients waiting for treatment.

Waiting List Data

A survey was conducted in the late 1980s to obtain information from 17 tertiary and secondary hospitals regarding the compilation and management of waiting lists. The findings suggested that there was a range of methods used to manage hospital waiting lists. Ten facilities reported compilation and maintenance of waiting lists by individual surgeons, 4 reported by surgical departments, and 3 reported by admissions/operating room departments.

All facilities collected various types of information including patient demographics, surgeon's name, diagnosis, and procedure. Some of the key problems with waiting lists in BC were: (1) waiting lists were maintained primarily by individual surgeons, (2) waiting lists did not distinguish between specific surgeon and hospital, (3) there were inconsistencies in the quantity and quality of the data, and (4) it was impossible to identify the factors responsible for the reported long surgical waiting lists. Researchers proposed that one of the options to be considered was the development of a central registry (Amoko, 1990; Amoko et al., 1992(b)).

Waiting lists for cardiac services and cancer services have been established at the provincial level. Following the waiting list crisis for cardiac services in the late 1980s, the Ministry of Health established a cardiac registry for all patients awaiting cardiac surgery in 1991. Unlike the Ontario experience, the registry serves to provide information and data on cardiac care and is not used to actively manage patients. In addition, the Ministry appointed a Provincial Advisory Panel on Cardiac Care comprised of surgeons and cardiologists to review waiting lists for cardiac care on an ongoing basis and to make regular recommendations to the Ministry (Katz et al., 1991). There is also a province wide cancer registry maintained by the BC Cancer Agency, mandated to provide cancer treatment to all BC patients. Chemotherapy and radiotherapy are provided in three major clinics and 24 community based centres (BC Ministry of Health, 1997).

In 1993, the Ministry of Health established the Surgical Waiting List Registry to track waiting lists and waiting times for all other surgical procedures. The registry is based on data submitted to the Ministry from 30 hospitals and represents over 1,000 physicians. Patient, physician and procedure information for all patients awaiting surgery are provided by hospitals to the Ministry on a monthly basis. The reported data include the date when patients are placed on the waiting list. Basic validity checks are conducted by the Ministry to ensure the data are reliable and consistent across sites. The data are used primarily to provide information regarding current waiting times and waiting lists in two ways. First, the data are used for the Provincial Surgical Registry Data Query System, software which provides up to date aggregated data on waiting lists by procedure, physician, hospital and region. This is

made available to all participating hospitals and additional clinicians (BC Ministry of Health, 1995). Second, the data are used to generate quarterly reports, the first of which was produced in the Fall of 1997 to report current waiting times and waiting list size for a range of procedures (BC Ministry of Health, 1997).

Recently, the British Columbia Medical Association (BCMA) has begun to collect information regarding waiting times for selected procedures (cardiac surgery, orthopaedic surgery, ophthalmology and rheumatology). The primary purpose of the BCMA effort is to collect data that reflect the entire waiting time experience from GP visit to surgical procedure. This was motivated in part by the release of the Ministry's waiting list report, which the BCMA argues does not represent an accurate picture of the amount of time patients are waiting. As previously described, the waiting time data collected by the Ministry of Health represent waiting times for surgical procedures only; that is, they do not include waiting time from GP referral to initial specialist consultation, nor waiting time between consultation and subsequent visits and/or diagnostic testing if required. The BCMA data are based on self-reports from specialists (n=319) within selected specialties. Physicians were asked to report waiting times for before (i.e. GP referral to consultation) and after consultation (i.e. consultation to surgery) for both urgent and elective cases. Physicians were also asked to provide information regarding acceptable waits. The results of the survey were provided in the first BCMA "Waiting List Report" in which waiting times were compared with those reported by the Ministry of Health. Given the differences in waiting time definition, it is not surprising that there were differences. The Association is expected to continue the survey bi-annually (BCMA, 1998).

Targeted Funding

Waiting lists for cardiac care had grown steadily during the late 1980s for various reasons, including shortages of critical care nurses and cardiac perfusion technologists, as well as a move to global budgeting for BC hospitals. In an effort to improve patient access to services, the Ministry used additional funding to contract with four Seattle hospitals to provide treatment to 200 patients. This was viewed as a short term solution. The first patient was sent to Washington State on March 13, 1990. Although the waiting list for cardiac services

continued to increase, only 185 patients were approved for surgery as of February 1991. There was limited interest among patients and, therefore, uptake was very slow. The policy was deemed to have had limited effect (Katz et al, 1990).

Since then, the Ministry of Health has continued to provide periodic additional funding to address waiting lists. Recent reports indicate that the Ministry spent a total of \$120 million between 1991 and 1997 (BC Ministry of Health, 1997a). This amount includes, for example, \$6.5 million for cardiac care and dialysis in 1997 and \$25 million for a range of services including cancer, cardiac care, orthopaedics, and dialysis in 1996 (BC Ministry of Health 1996, 1997b; Fayerman, 1997). Additional resources represent just one part of BC's efforts to address the waiting list situation. The province has adopted a range of initiatives as outlined below.

Effects of Waiting List Policies

No formal evaluation have been undertaken, or at least published, other than the work of Katz. The Ministry of Health report claims that progress has been made regarding waiting times for selected procedures, including cancer treatment, hip and knee surgery, cornea transplants and coronary angioplasty. Median waiting times for knee replacement, for example, decreased from 14.9 weeks in 1995 to 11.3 weeks in 1997. The Ministry attributes the reduction, in part, to increased funding. Waiting times for cataract surgery decreased by less than 1 week from 8.1 weeks to 7.3 weeks during the same time period. The Ministry also noted that while waiting times for cardiac surgery increased from 11 to 14 weeks between 1995 and 1997, a \$4.3 million investment in cardiac surgery has served to reverse the trend in the latter part of 1997 (BC Ministry of Health, 1997 a). While the results appear encouraging for some procedures, this represents a very short-term informal descriptive evaluation. Given the experiences of other countries, targeted funding should not be expected to have lasting effects on waiting times.

7.5.3 Nova Scotia

Waiting List Data

As part of an overall effort to evaluate changes in the health care system, Nova Scotia has focussed on the development of key measures and indicators to monitor the overall health effects of the range of health care services provided in the province. Once such indicator focusses on waiting times for elective surgery. The indicator is used to provide “some insight into how well the health care system is serving the public” (Nova Scotia, 1997). Waiting time for elective surgery was defined as the time between when the decision to proceed to surgery was made and the date of surgery. It represents a retrospective measure of waiting times calculated using MSI physician claims data for years 1990 to 1994 for 100 elective surgical procedures. A claim is submitted for every insured service provided by a physician and includes information regarding patient identification, service(s) provided, diagnosis, date and other details.

Relevant elective surgeries performed between 1992 and 1996 were examined. A total of 347,000 services were identified representing 75% of all major procedures conducted during this time period. All specialist visits prior to surgery (e.g. consultation, continuing or directive care, routine office visit) during a 36 month period were used to create episodes of care for each patient. The specialist visit prior to surgery was used as a proxy measure of date on the waiting list. For cases with more than one specialist visit prior to surgery, the last visit was used as a proxy measure for date on the waiting list. This method assumes that the decision to have surgery is made during this final visit. Procedures performed within three days of the last specialist visit were excluded since they may have been acute or urgent procedures. In 75% of cases, patients had only one specialist visit prior to surgery. Total waiting times, therefore, were calculated to be the time between the last specialist visit and the date of surgery for surgical procedures (Nova Scotia, 1997).

The results of the analysis were reported in a public document released by the Department of Health entitled, *Reporting Health Performance: Elective procedure waiting times in Nova Scotia 1992-1996*. Average waiting times for selected procedures such as hip and knee replacement and cholecystectomy, has decreased between 1992 and 1996. Waiting times

increased for other procedures such as ear, nose and throat. Selected regional analyses indicated the presence of some degree of inter-regional variation in waiting times. The report represents the first initiative for tracking waiting times in the province. Future plans include the use of MSI data to track waiting times for a wider range of procedures in an automated system (Nova Scotia, 1997).

Like many other provinces, Nova Scotia has had to address the issue of waiting lists for cardiac care. Cardiac care is provided in a single hospital, The Queen Elizabeth II Health Science Centre, which also provides specialized services to other Atlantic provinces. The hospital has long maintained a waiting list for cardiac care which serves as a single entry to care, used to manage patients based on the use of priority criteria. The hospital is considering the development of methods to provide valid and reliable waiting times data for a range of other procedures (Nova Scotia, 1997).

7.5.4 Other Provincial Initiatives

Most of the remaining provincial and territorial Ministries of Health have had to address the issue of waiting lists. While there is limited information regarding the nature of these efforts, it appears that most governments have adopted the policy of targeted funding to reduce waiting lists and waiting times for selected procedures. Alberta, for example, allocated \$41 million for cardiac care, cancer treatment, transplants and neurosurgery, and an additional \$11.4 million for new equipment to reduce waiting lists for diagnostic tests in 1996/97 (Alberta Health, 1996 a,b). Likewise, Manitoba, allocated \$500,000 to address orthopaedics, radiation, cardiac care and MRI waiting lists in 1995 and \$77,000 to reduce waiting time for bone density testing in 1997 (Manitoba Health, 1995; 1997 a,b).

Based on selected information from these provinces, it appears that governments are taking action in an attempt to reduce waiting lists and waiting times. What is not often clear is whether these policies are having any short or long-term effects. There is no information available regarding the effects of these policies on waiting lists and/or waiting times.

7.6 Lessons Learned

The experiences of governments both within Canada and abroad provide some valuable lessons regarding policy options to address waiting lists and waiting times. As previously discussed, these policies can be grouped into two basic categories: “supply-side” policies and “demand-side” policies. There is a third category comprised of government actions which focuss on data gathering and monitoring.

Waiting List Data

- ▶ Reliable and valid waiting list data are required to determine the current state of waiting list size and waiting times and to monitor the short and long term effects of various “supply” and “demand” policies.
- ▶ The data should be collected in a consistent and comprehensive manner with clearly stated and validated criteria for determining “date on” and “date off” in order to ensure comparability at various levels (e.g. regions, hospitals).
- ▶ The data should be collected by specialty and procedure since waiting list size and waiting times vary between procedures and may be affected differently by different policies.
- ▶ To date, waiting list data has been used primarily to monitor and report the current state of waiting lists and waiting times. It has been suggested that waiting list information can be used to effect change in referral patterns. If health care providers have access to waiting list information for individual physicians and hospitals then patients can be referred to those with the shortest waiting times. This would result in a redistribution of patients and potentially lead to shorter waiting times and waiting lists (Yates, 1987). While this option has not been fully explored or researched, preliminary evidence suggests that providers are not always willing to change referral patterns when given the opportunity (Hanning et al., 1996).

“Supply-Side” Policies

There have been various “supply-side” policies adopted to date which focus on increasing the number and type of health care services provided, primarily through increased funding, in order to reduce waiting lists and waiting times. The following lessons can be drawn from these experiences:

- ▶ Additional funding allocated to reduce waiting lists and/or waiting times should be specifically targeted, as was done in the UK, Sweden and a number of Canadian provinces to reduce waiting list size and eliminate long waits. This will ensure that the funds are not used for other purposes.
- ▶ Targeted funding can provide short-term relief to reduce backlogs and temporarily clear waiting lists.
- ▶ Targeted funding DOES NOT necessarily provide a long-term solution to waiting lists. Increases in admission from waiting lists are often followed by an increase in the addition of new patients, resulting in an overall increase in waiting list size.
- ▶ Targeted funding can provide short-term reductions in average and median waiting times if funds are specifically used to provide services to those patients waiting longer than a specified period of time (e.g. 18 months, 2 years) or to guarantee patients medical care within a specified period of time.
- ▶ Policies which target resources for patients who have waited a specified period of time (e.g. > 2 years) may have a detrimental effect on accessibility to health care if services are provided at the expense of patients who do not meet the criteria (e.g. waiting time < 2 years).
- ▶ Targeted funding DOES NOT necessarily represent a long-term solution to excessive waiting times. In most cases, reductions in waiting times are not

sustainable following a period of additional funding.

- ▶ There is no evidence to suggest that private sector health care will result in shorter waiting lists and waiting times in the public sector. Providing access to private care for those who can afford and choose to pay has, if anything, perverse effects on waiting lists and waiting times in the public sector. Greater access to private care appears to be generally associated with LONGER public sector queues.

“Demand-Side” Policies:

The “demand-side” policies adopted to date have focussed primarily on the management of waiting lists and include appropriate prioritization of patients awaiting medical or surgical care through the identification and weighting of appropriate criteria.

- ▶ The development of selection criteria for waiting list placement can serve to ensure that only those patients for whom services are medically necessary are placed on waiting lists.
- ▶ Consensus panels can be used to develop procedure-specific priority, as has been done for coronary artery bypass surgery. This can serve to ensure that patients are appropriately prioritized and managed while on a waiting list.
- ▶ Consensus panels can also be used to determine acceptable waiting times for specific groups of patients based on clinical and other criteria. This appears to be a valid and reliable method of determining acceptable or reasonable waiting times, if it is evidence based.
- ▶ While selection and priority criteria can be used to effectively manage and monitor patients on at least some waiting lists, their effect on waiting list size and waiting times has not been thoroughly investigated.

Chapter 6:

Policy Implications and Recommendations

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1.0 Summary of Findings

A number of over-arching impressions emerged as consistent themes from the literature synthesis and the surveys and interviews:

- ▶ few currently operational wait lists in Canada, or elsewhere, are sufficiently defined and standardized to provide inter-temporally consistent and geographically comparable databases. It is therefore impossible either to understand the true magnitude of wait lists or to genuinely and rationally manage the patients on those lists. In the absence of such information, provincial/territorial activity has been largely limited to addressing specific wait list 'problems', often 'surfaced' by specific episodes of media attention, through short term increases in funding;
- ▶ with rare exceptions such as cardiac and cancer care in some jurisdictions, there is an almost total absence of consistently applied criteria (within procedures, let alone across) for determining when patients should be added to wait lists, and how they should be prioritized. As a result, it is virtually impossible to know how to interpret any particular claims about the length of time patients are currently waiting for any particular procedure, and reports based (ostensibly) on the same patient populations can produce substantially different estimates of median wait times (as was the case recently in British Columbia);
- ▶ as many as 20-30% of those on wait lists are found, consistently in the international literature, to be inappropriately placed, because they have already received the procedure, they have died, they never knew they were on a list, they were placed on the list in the first place for reasons unrelated to medical necessity, or they were no longer awaiting the procedure for some other reason;

- ▶ provincial/territorial government interviewees were reasonably consistent in identifying orthopaedics, cardiac, and MRI as types of services for which they believe that access is a current concern;
- ▶ key factors identified as being implicated in the persistence of extensive wait lists (again by provincial/territorial government interviewees) were, in the opinion of respondents, availability and co-ordination of relevant health care personnel, an aging population, and patient "behaviour" (e.g. patients wishing to wait for a particular physician);
- ▶ provider, administrative and consumer group respondents to similar questions identified "provider shortages", "aging population" and "patient expectations" as some of the key factors underlying the existence and persistence of excessive wait lists (within this group of respondents, fewer than 50% were actually familiar with, or participated in the creation of, waiting lists);
- ▶ evidence-based measures of clinical urgency, that take account of issues such as potential deterioration in quality of life or clinical condition, were viewed as the most important criteria for determining whether a patient should be on a list, and assigning priority to the patient;
- ▶ most policy initiatives directed at perceived wait list/time crises have been "supply side" (i.e. more funding, new resources), rather than "demand side" (more consistent criteria governing how patients come to be placed on lists, and management of them once on lists);
- ▶ international experience suggests that targeted additional funding provides, at best, short term reductions in wait list size and/or median wait time. There is no extant evidence suggesting that such reductions are sustainable in the longer term;

- ▶ international experience suggests that where private and public financing co-exist, and particularly where the same practitioners provide care to both public and private patients, wait times tend to be longer in the public sector.

2.0 Policy Recommendations

These findings lead to the following suggested set of policy avenues, which cluster into four general areas: definitions/criteria; management/accountability; resources/funding; information/research/evaluation.

2.1. Definitions/Criteria

Standardized methods for measuring and reporting waiting times must be developed. This requires, inter alia, the development of criteria for determining whether a patient should be placed on a wait list, consistent approaches to defining "time on" (that is, when a patient should be placed on a wait list), and continuous monitoring to ensure that patients are appropriately prioritized and that those who no longer need to be on lists are removed. The determination of clinical priority will require a much more concerted effort, across jurisdictions and clinical conditions, to develop operational measures of clinical severity which embody criteria regarding the "potential to benefit" and risk of deterioration (clinical and quality of life). With few exceptions (e.g. cardiac surgery, radiation oncology, and even for these, only in some jurisdictions), such criteria and definitions are noticeable largely by their absence, in Canada and elsewhere. There is a clear national role in the development and application of standards and consistent criteria.

The process through which such standards and criteria would be developed requires the participation of those with relevant clinical and measurement expertise who also satisfy two other key requirements: they must have no clinical or economic stake in the criteria, and they must have strong skills in the critical appraisal of clinical (and other) literature.

2.2 Management/Accountability

At present most wait lists in Canada appear to be maintained either as solo efforts by individual clinicians or in single institutions. There is little or no communication about wait lists among clinicians or institutions even within the same geography and specialty. Taken in conjunction with the observations above about the absence of consistent wait list/time criteria and definitions, this points to a clear need for the development of a system (or systems) of management and accountability in this area. At the most micro level, mechanisms should be put in place to hold individual clinicians accountable for the placement and prioritization of their patients on lists. Periodic audits (a critical function of any concerted management process) should be used to ensure that clinicians are made aware of inappropriate use of wait lists. At the regional health authority and provincial levels, mechanisms need to be developed for integrating lists and prioritization across clinicians or institutions, and for providing continuous information to referring physicians and their patients. Again, audits should be used to monitor and fine-tune this process. For unusual conditions, or where the necessary case load does not support capacity in all jurisdictions, regional, cross-provincial, or even national registries (with the attendant management/accountability) should be developed and maintained.

A number of alternatives to individual-clinician- or institution-held wait lists should be explored, through the use of pilot initiatives at the regional authority, provincial, and even cross-provincial levels. It is not clear that patients, clinicians, or managers are best served by the current ad hoc mix of 'systems'. There is a clear need for integration/collaboration, within and between specialties, in order to ensure that patients requiring the same clinical 'space' reach needed services or interventions in an order reflecting their relative clinical need.

2.3 Resources/Funding

None of the activities described above can materialize without a commitment of time and funding. The development of consensus criteria, the monitoring and adjustment of wait lists once developed, the development of shared registries, and the ongoing auditing of wait lists, all point to the need for a significant investment in wait list infrastructure. Without such an investment, we can anticipate that the current state of chaos, misinformation, and scare tactics, will continue unabated. Moreover, patients will continue to suffer because of inappropriate

placement, rigid lists, gaming and other problems clearly identified through interviews and the literature.

There is also a need for the development of consistent criteria that will be widely accepted and that can be used to ascertain when a wait list is at a point where it "requires attention" (i.e. all patients on the list should be on, but wait times are exceeding the evidence-based and clinically accepted thresholds beyond which there is likely to be deterioration in outcomes). In such situations, the responsible jurisdictions must be prepared to provide additional funding or capacity, in order to re-establish acceptable wait times. Any such initiative must only be undertaken in an environment where the criteria, monitoring, and audit functions are in place, so that increased funding or capacity do not simply result in longer wait lists, as has been found in a number of other jurisdictions.

As noted above, a key (but certainly not the only) human component of this infrastructure is clinicians skilled in critical appraisal and clinical practice guidelines processes. There is a dearth of such individuals at present in this country. Training more should be a funding priority.

Targeting resources to the areas described here will require concerted commitment and participation from all levels of governance, from the federal government, to individual institutions. The federal role in this respect could take a number of forms, including but not restricted to facilitating the development of criteria and standards (through targeted funding initiatives), participating in the development of national wait list registries where appropriate (e.g. for rare conditions where cross-provincial integration of wait lists would make sense), facilitating the production of routine comparative wait list reports, and funding specific research projects (pilot and other) where insufficient information currently exists (e.g. in our understanding of the factors and mechanisms affecting wait lists and wait times; or in the evaluation of particular approaches to reducing these, such as guaranteed maximum wait time policies).

Provincial governments have an obvious stake in ensuring effective and appropriate wait list systems to ensure adequate access and efficient use of limited resources. But it does not

follow that each province/territory needs to develop its own infrastructure for all purposes described above. Indeed, collaboration (particularly interprovincially) would seem to be warranted. At the regional health authority level (where such exist), regions, institutions and individual clinicians will need to work together; funding for efforts most logically situated at these levels should be provided through regional budgets.

And finally, despite repeated calls for private financing to relieve an over-taxed public system, we could find no evidence, from Canada or elsewhere, to support this notion. Indeed, if anything, the evidence points in the opposite direction - where we find private funding, we find generally worse access for publicly funded patients, particularly in cases where physicians are serving both public and private patients.

2.4 Information/Research/Evaluation

A key finding from the literature synthesis and our interviews was how little reliable and consistent information is available, and how little is understood about the mechanisms through which patients come to be placed on, prioritized, and removed from, wait lists. In addition, there is remarkably little evaluative work in this area from which one could draw firm conclusions about the effects of different approaches to managing wait lists and times. For example while some research has shown that providing additional funding for some procedures provides short term 'relief', in the medium to long term, it simply results in increased wait lists. What is unclear is how generalizable these results are - they do not rule out the possibility that unacceptable waits for some procedures may be reduced, on a more permanent basis, through strategic funding.

While there is plenty of 'research' out there, there is no critical mass of valid and generalizable evidence identifying factors and mechanisms affecting wait lists and wait times. Such evidence is essential if policy development is to be guided by evidence rather than rhetoric, and if we are to avoid 'traditional solutions' (e.g. throwing money at the problem) which have been found largely wanting. Health Canada and other national funding bodies (e.g. Canadian Health Services Research Foundation, MRC) should play a central role in this respect, both through targeted research funding, and in the encouragement of widespread dissemination of the results emerging from such research.

Continuing research on the impact of new technologies will be critical to advances in the management and prioritization of patient access. This will involve technology assessment activities to ensure that information from such assessments is fed into the process of developing criteria and standards. Long wait lists for ineffective procedures may be a concern, but not for the usual reasons.

Finally, as consistent, valid and reliable measures of wait lists and wait times become available, they should be routinely and widely reported, so that clinicians, regions, and provinces/territories can monitor the management of lists relative to other jurisdictions, in order to determine whether resources need to be re-allocated. Until such time as the developmental work described above is in place, we are not convinced that reporting of wait list length or times on the basis of current methods and information (with the important exceptions noted earlier) plays any useful role. On the contrary, it is almost certainly misleading, and is guaranteed to continue to "create mischief" and provide a steady stream of sound-bites to a voracious, and too often uncritical, media.

Consideration should be given to sponsoring a high-profile national conference on the nature of the data and management problems, and the need for a 'concerted action' in this area. Such a conference would bring together the key constituencies and the media, as a first step in building support for the research and development activities outlined above, and to educate interested groups (media, regional health authorities, clinicians) regarding the importance of responsible use of data and anecdote.

3.0 Final Observations

From the above summary it should be abundantly clear that access to many types of procedural care in Canada is poorly managed, and even more poorly understood. There is a critical need for the systematic development of information systems populated with consistent and reliable information, that can form the basis for more appropriate management strategies, and that can provide a reliable 'early warning' system for policy initiatives. Our current understanding of the 'wait list situation' in Canada is so totally dependent on data of suspect quality, drawn from a variety of ad hoc sources, based on inconsistent definitions, used for a

variety of purposes, and overseen by no one, that it is little wonder that we find so much confusion. There may be situations where "more money" would provide more than short-term palliation, but to date there is no evidence to support any such claim. The overarching need in this area is for more and better management, and careful evaluation of new initiatives. This cannot take place without the requisite information infrastructure. And until we have "more management", whether "more money" is needed to alleviate truly critical wait list situations will continue to be the million dollar question.

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